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The Medicare Hospice Benefit: Peering Into the Black Box

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Dedication

This dissertation is dedicated to my husband, Ehren, my children, Ezra and Esther, and my parents, Gaylord and Debra Herbert.

Abstract

The Medicare Hospice Benefit (MHB) provides terminally ill Medicare beneficiaries with a program of care specifically targeted to shifting the goals of medical care from curative to palliative care. The American Society of Clinical Oncologists (ASCO) considers hospice to be the optimal system of care for patients with cancer who are dying.

This research evaluates use of the MHB among patients with cancer using the Surveillance, Epidemiology and End Results (SEER)-Medicare linked database. We use novel methodologies and data fields which have only recently become available to understand whether these patients are using the MHB as expected given its design.

The Peters-Belson method is used to understand the disparity in hospice use between blacks and whites over time in patients with terminal cancer diagnoses (pancreatic, lung and advanced gastric cancers). We find that while use of hospice has grown for both groups, the observed disparity has increased from 1992 to 2008 while the difference between the observed and expected disparity (based on differences in population factors between the groups) has increased over time from <-1% to 33%.

We also find that patients with lung cancer who use no cancer directed treatment use hospice at the same rate as patients who use three or more cancer directed treatments (adjusted odds ratio (OR) of 0.892 (95% CI: 0.775-1.026)). Patients who use two or more treatments are significantly less likely than patients with three or more treatments to use hospice (OR=0.838, 95% CI: 0.728-0.965).

Finally, we find that 30% of hospice patients with cancer do not die at home, despite the home-based design of the benefit. Almost half of hospice users who died in the

hospital had a total length of stay of 3 days or fewer, and two-thirds had a length of stay less than 1 week, suggesting a shift to the hospice payment system without time to benefit from the system of care.

Our results demonstrate the continuing importance of monitoring and investigating disparities in hospice use, expanding access to palliative care for patients who use cancer directed treatment, and reforming payment incentives for hospice care provided in institutions.

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Introduction

Hospice is a program of health care used at the end of life that involves a shift in treatment focus from curative care to pain and symptom management. The American Society of Clinical Oncology has identified hospice as the best system of care for patients who are dying,[1] and because hospice is associated with positive outcomes for both patients and bereaved family members,[2,3] use of hospice is often used as an indicator of quality of care at the end of life.[4] Medicare has covered hospice care since 1983. Use has grown tremendously in the last two decades; almost half (45.2%) of Medicare beneficiaries who died in 2011, over 1 million people, used hospice.[5]

Hospice is most helpful to the patient when initiated more than one week prior to death[4,6] and many argue for an even longer time frame to benefit.[7,8] Timely referral to hospice is easier when the prognosis is more certain.[9] Patients dying of cancer have a relatively predictable decline prior to death making the recognition of the end of life more obvious.[10] Hospice was, in part, designed for patients with cancer and their families who needed pain and symptom management and emotional and spiritual support as they faced death but wished for care outside of a medical institution.[11] The arsenal of treatments for cancer is constantly growing.[12–15] To access the Medicare Hospice Benefit (MHB), however, patients must discontinue use of curative or life extending treatment.[16]

Most discussions of the use of hospice implicitly contain three assumptions about hospice based on the facts above. First, the assumption that increased use in recent years signals the availability of the benefit to any who wish to access it. Second, an assumption that hospice is a substitute for aggressive care because patients must stop receiving

reimbursement for aggressive care when they enroll in hospice. Third, because the MHB was designed to be a home-based benefit, the assumption that death in hospice means that the death occurred at home. This dissertation will examine these assumptions in three analyses answering the following questions:

(1) Has the disparity in rates of hospice use between blacks and whites lessened over time with increased access to hospice?

(2) Does receipt of aggressive cancer treatment affect use of hospice?

(3) Where do hospice patients die?

By understanding the empirical data regarding these assumptions, hospice advocates and policymakers will have a greater understanding of how the MHB is currently being used and where improvements are needed.

Background and Motivation

The Medicare Hospice Benefit

The MHB was created in 1982 to provide all Medicare beneficiaries who have a life expectancy of six months or less financial access to hospice programs.[17] The hospice program is required to provide nursing and home health aide services, drugs for pain and symptom control, and counseling, and may provide physical, occupational, and speech therapy, and other services.[16] The MHB is available to beneficiaries enrolled in either managed care (HMO) or fee-for-service (FFS) Medicare; for those enrolled in managed care, it is a "carve-out" benefit—payment comes from CMS rather than from the managed care company. Patients may not receive Medicare reimbursement for treatment aimed at curing their terminal condition, but they may receive Medicare reimbursement

for treatment of unrelated conditions.[18] For example, a person with lung cancer who is being treated for diabetes must relinquish reimbursement for lung cancer treatment but can continue to receive reimbursement for diabetes care. Medicare is the primary payer for almost 80% of hospice discharges.[19]

Medicare pays hospices on a per-diem basis; the payment rate depends on the level of care provided each day. Almost 97% of paid days are 'routine home care' (RHC).[5] Under this payment rate, the patient usually resides at home and is expected to have a caregiver, usually informal such as a friend of family member. A hospice staff member visits to provide care, and the per diem rate is billed for every day the patient is enrolled in hospice, regardless if a visit is made on that day. If the patient is in crisis and requires more attention from hospice staff but remains where they reside, the day is billed at the 'continuous home care' rate. If the patient's primary informal caregiver needs a break, the patient may be admitted to an inpatient facility and the days are billed as inpatient respite care. Finally, if there are symptoms for which management requires inpatient care, the care is billed at the general inpatient care rate (GIC). The hospice covers all services provided out of the per diem payments collected.[5,18]

Hospice use is associated with improved quality of life for patients and families of patients. Hospice staff specialize in symptom management for dying patients, which results in improvements over other care models.[2,3] Psychosocial and spiritual care for both the patient and their family members leads to greater satisfaction and aids the bereavement process.[3,20,21] Some say the greatest benefit to hospice users is the acceptance that death will occur soon which provides the chance to get "affairs in order"

and take the time to say goodbye to loved ones, a process facilitated by the hospice.[22] In surveys of how people wish to die, the majority of people respond "at home" and "surrounded by loved ones," situations promoted by hospice and not by traditional institutional care.[23–25] Yet the rate of patients with terminal conditions enrolling in hospice is lower than expected, based on these benefits.

Most Medicare beneficiaries have, at minimum, financial access to hospice. The MHB is available to all persons enrolled in Part A (Hospital Insurance) and requires no additional costs beyond eligibility. The MHB has historically been one of the most generous Medicare programs for patients, requiring very minimal copayments and including payment for drugs. While not all persons who die could benefit from hospice (because a death may be unexpected), it is generally accepted that many more patients are eligible for hospice than choose to use the benefit. A recent study of deaths in one hospital found that 60% of patients who had been admitted at least once before in the previous year where hospice eligible at the time of the penultimate admission.[26] This could indicate lack of access to hospice, patient preference or lack of knowledge of hospice eligibility. In the previously described study, only 14% of the hospice eligible patients had documentation of a discussion about hospice.[26] Yet reported preferences of most patients for the end of life include good pain management, presence of family and friends, a familiar environment and avoidance of technology intensive hospitalizations[27]-- all of which occur more often in hospice.

Barriers to access to hospice care include: certification of a life expectancy of less than 6 months, willingness to forgo life extending treatment while under hospice care,

access to informal caregiver(s) to care for the patient at home, and having hospice services available geographically.[28,29] These barriers result in subpopulations of patients who are less likely to receive care based on non-medical factors.

Variation in use of hospice

African American and Latino patients have significantly lower rates of hospice use than European Americans.[30,31] Some conjecture a general preference for aggressive rather than curative treatment at the end of life among cultural groups;[32] while the majority of Americans would prefer to die at home, subgroup analysis in one study found that 62% of African Americans would prefer to die in a hospital.[33] It is noteworthy that while hospice diffused across the population in the 1990s and reduced the variation in hospice users, the disparity between blacks and whites was largely unaffected.[34] However, other factors may also play a role in the disparities: mistrust of the health care system, lack of knowledge of end of life care options (possibly due to the poor quality of care, as discussed above),[35] or lack of access to care.[36].

There are also documented geographic differences in hospice use, which could stem from health system differences, cultural differences or both. Hospice use has been found to be higher in the South and Southwestern US and lower in the Midwest and Northeast. State rates of hospice use prior to death varied from 8% to 49%.[37] Virnig et al.[38] found that in 1996, rates of hospice use in large metropolitan statistical areas (MSAs) varied from 35.15 to 397.2 per 1000 deaths. Persons living in wealthier areas and in urban areas also had significantly higher rates of hospice use than their less wealthy and rural counterparts, respectively. Hospice use was positively related to

average reimbursements for health care and physicians per capita[38] and unassociated with reported patient preference for aggressive treatment differences in geographic areas.[39]

Other health system characteristics, such as enrollment in FFS Medicare versus Medicare HMO are important despite geographic location.[40,41] Physician incentives within HMO settings are consistent with increased use of hospice and with fewer patients experiencing very short lengths of stay in hospice.[42] Patient factors interact with the payment system in varied ways as well. Income impacts hospice use differently in HMO or FFS Medicare, while other factors, such as race, impact hospice use in much the same way regardless of insurance type.[43]

Quality care at the end of life consists not only of enrolling in hospice prior to death but also of using it for long enough to achieve benefit.[4] The length of time a person lives after enrollment in hospice has been found to vary by patient and hospice characteristics. Male sex, white race, and disease burden are associated with shorter survival after hospice entry.[44] Enrollment in FFS Medicare or a Medicare HMO impact length of stay in hospice as well.[40,42] Characteristics of hospices, such as for-profit status, large size, and being newer are also associated with shorter enrollment periods.[45]

Variation in use, length of stay, and cost savings at the end of life are the most common lines of inquiry for studies of hospice. Relatively little attention has been paid to the care received prior to hospice entry or death, including the care surrounding the terminal diagnosis. Yet when patients are asked to forgo further treatment for their terminal condition in order to enroll in hospice, one might expect that the diagnosis

experience itself and the care received might have impact on that choice. Variations in cancer diagnosis and treatment are also widely documented.

Variation in cancer diagnosis and treatment

Variation in cancer care can be seen early in the course of medical care impacting timing of diagnosis. Disparities in screening and general access to medical care result in disease that is more serious upon diagnosis. For cancers for which screening is available, participation in screening varies by race and ethnicity, age, sex, and measures of socioeconomic status (SES) such as years of education, health insurance status, and poverty.[46,47] Singh et al[47] found that for female breast cancer, cervical cancer, prostate cancer, and colorectal cancer, the proportion of African Americans, Hispanics/Latinos and American Indians/Alaskan Natives diagnosed with regional or distant disease is significantly higher than for Whites and Asian Americans/Pacific Islanders. Disparities in stage at diagnosis by race and SES (area poverty rate) are also found in cancers for which screening is not available, such as lung cancer.[46,47]

Differences in mortality rates for cancer are also well documented but cannot be completely attributed to late discovery of the disease. Disparities in diagnostic evaluation after diagnosis also occur, and this is important because diagnostic evaluation provides information about the extent of disease, which will determine the most appropriate initial course of treatment. For example, after diagnosis of cervical cancer, African American women are more likely than white women to remain unstaged and receive no treatment.[48]

Studies of cancer treatment among races have found that outcomes of a treatment are similar if patients receive the same treatments and supportive care; however, in the

general population, stage-specific survival is not equal among races. While there is evidence for increased survival with chemotherapy treatment for ovarian cancer among all races, rates of use are lower for black patients.[49] Rates of recommended treatment for early stage non-small cell lung cancer differ by race, even after controlling for income and insurance coverage.[50]

In summary, the contribution of non-medical factors to the diagnosis and treatment of cancer impacts outcomes for patients. Patients who do not receive recommended care may be less likely to enter remission from cancer, have cancer recur sooner, and/or die from the cancer sooner. Variations in quality of care at one point in time of the illness will impact future events for the patient.

The factors influencing care at diagnosis are the remarkably similar to those found to influence the use of hospice (Table 1). While cancer causes a relatively predictable period of decline prior to death, hospice participation could not conceivably reach 100 percent among cancer patients. Death may come suddenly due to complications of treatment or other causes unrelated to the cancer. Also, some patients may prefer not to enroll in hospice so that they can pursue cure or life extension or they may prefer a non-hospice setting for death. Similarly, patients may have differing treatment preferences for cancer care. However, the variations in hospice use and cancer care seen from the population-level are *systematic* and do not suggest that personal preference alone can explain these subgroup variations.

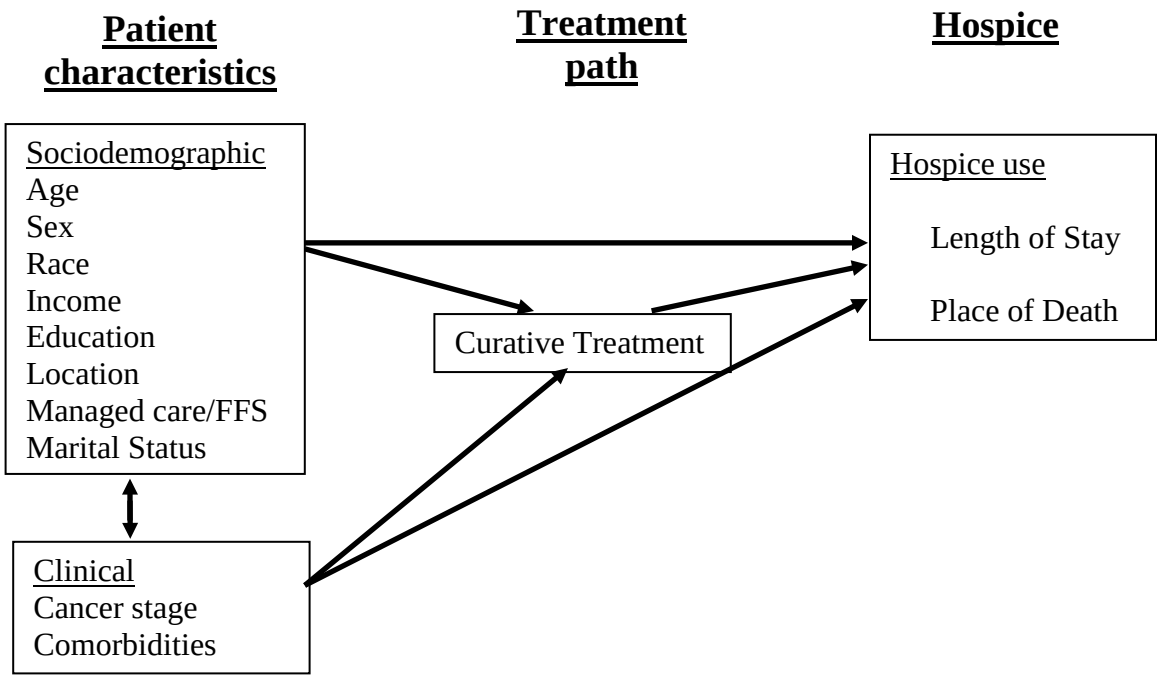
Table 1. Similarities between factors influencing initial cancer care and use of hospice

Factors influencing care	Influence on:	
	Initial workup/treatment	**Hospice care**
Age	As age increases, aggressiveness of care decreases [51,52]	As age increases, use of hospice care decreases[31]
Sex	Women tend to have less aggressive care [53,54]	Women tend to use hospice less[55]
Race/Ethnicity	African American women more likely to remain unstaged after diagnosis[48] Lower use among African Americans and Latinos [50]	Lower use among African Americans and Latinos[30,31]
Insurance	Earlier stage at diagnosis and increased use of adjuvant therapy in Medicare HMO[56]	Medicare HMO patients use hospice at a higher rate than FFS patients [40,42]
Time	Increased use of chemotherapy/radiation in initial treatment [57]	Increased use of hospice over time [58,59]

Research plan

With this background in mind, I propose a conceptual model that incorporates both hospice and other treatment options available to patients with a cancer diagnosis (Figure 1). Patient sociodemographic characteristics influence the cancer diagnosis as well as access to and preferences for both curative treatment and all aspects of hospice use (use, length of use and place of death). Whether curative treatment is used determines use of hospice including how long hospice is used and where it is used. This conceptual model forms the basis of the three studies of hospice care, each of which is discussed in detail in the following pages.

Figure 1. Conceptual model



Assumptions about hospice

Access

Since the inception of the MHB, the numbers of patients using hospice prior to death has grown dramatically. During the same period, the percentage of people using hospice for less than one week prior to death has increased, meaning that some are using hospice as a "place" to die rather than a means of care prior to death. This is concerning because the benefit of hospice as an interdisciplinary care team providing physical, emotional, and social support prior to death is minimized when the patient enters hospice only after he or she is actively dying. Although use of hospice prior to death and length of stay in hospice have been suggested as indicators of quality care at the end of life,[4]

trends over time show improvement in use of hospice but decline in optimal length of stay (i.e., more than 7 days but less than 180 days).

Despite increasing hospice use among all races as the number of hospices has grown, a significant disparity in use of hospice prior to death remains between non-Hispanic blacks and non-Hispanic whites in the Medicare population.[60] Some studies of length of stay in hospice, including internal analyses, have found that median length of stay of non-Hispanic blacks and Hispanics in hospice is similar to if not greater than the median length of stay of non-Hispanic whites.[40,58]

There have been no studies to my knowledge examining trends in the use of hospice for what is considered an optimal amount of time (more than 7 days but less than 180 days). Lengths of stay of less than 7 days has been considered a "short" hospice stay in the literature since the 1990s,[9,45,61]although a few have suggested that three days would more appropriately describe a stay too short to benefit the patient.[4] Stays greater than 180 days are considered "long use," and again question the benefit of highly specialized care for the dying patient when the patient instead lives so long that they may have achieved greater benefit from rehabilitative care.[9] A length of stay of 180 days also coincides with the end of the second ninety day hospice benefit period, after which patients need to be recertified as eligible for the benefit every 60 days.[16]

Our first analyses will focus on whether the disparity in hospice use between whites and blacks has changed over time and how differences between the populations in factors associated with hospice use, such as age at diagnosis, geographic location, sex, marital status, income and Medicare payment system explain hospice use over time.

Both overall use of hospice and optimal use of hospice will be measured due to the trend in a decreasing proportion of optimal use among hospice users.[59]

Preference for less aggressive treatment

Those who use hospice are generally believed to have a preference for less aggressive treatment.[62,63] As described by Beeuwkes-Buntin and Huskamp:[29] "there is likely to be selection bias associated with the use of hospice: Individuals who choose hospice are less likely to have pursued aggressive intervention even if hospice was not an option" (p.42). Cost studies of hospice have shown this not to be the case: prior to entering hospice, hospice users do not appear to have a preference for less aggressive care. "However, some researchers did not find hospice enrollees to have a lower propensity for hospitalization, at least before hospice enrollment; they found in Months 2 through 6 before death (before hospice enrollment for most dying in hospice care) that average healthcare costs were significantly higher for hospice versus nonhospice decedents".[64] "Evidence from the evaluation suggests that [Medicare Hospice] benefit enrollees were terminally ill and heavy users of health services longer than the average non-benefit patient".[65] While patients enrolled in the hospice benefit necessarily use fewer resources for their terminal condition once enrolled, due to the benefit's design, this analysis questions whether the amount of curative of life extending treatment received is associated with hospice use.

Studies seeking to understand who chooses to use hospice have focused almost exclusively on the time period immediately prior to death, examining associations between demographic, socioeconomic, geographic, and market factors and use of hospice

prior to death. However, a large experimental study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)) and anthropological studies observing care of seriously ill patients, have given evidence against the notion of a single decision to discontinue life extending treatment at the end of life.[66] Instead, they argue for "pathways" of treatment: the absence of discrete decisions in favor of "usual next steps."[66–68] A pathway is comprised of a series of medical treatments or tests over time, with each step depending upon the outcome of the last. Diagnostic and treatment algorithms, based on evidence, exist to inform the next step and become the routine—once on the pathway, it becomes difficult to deviate from the routine. When the first treatment fails, the next is tried. It becomes difficult to inset the hospice "choice" before all existing treatments have been tried. If this is the case, we hypothesize in our second paper that we will observe more hospice use with more treatment.

Home death

The early hospice movement and the MHB focused on moving end-of-life care out of institutions and into the home. The placement of the MHB in the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)[17] is indicative of the hope for the benefit—to shift costs from the Federal government back to families. One piece of this is increasing the reliance on informal caregivers, usually friends and family members. The benefit's capitated design and explicit caps on the number of inpatient days allowed would lead one to expect that most deaths occur in the patient's home. Yet the increase in very short stays in hospice may make it unlikely that patients have time to transition to home if they

received care in an institution, and the increase in use of hospice in nursing homes make these likely places for hospice death as well.

Several single institution and single system studies have suggested that many patients do not die at home.[69–71] New information on location of service in the Medicare administrative data allow us to assess national trends in place of death for elderly patients with cancer who used hospice. Our third analysis will examine the relationship of demographic factors such as age, race, geographic location, marital status, Medicare payment system to understand factors associated with place of death among hospice users.

Data

Our study used SEER-Medicare linked data, which provides a unique opportunity to study this topic. The SEER (Surveillance, Epidemiology and End-Results) Program is a collection of population based tumor registries headed by the National Cancer Institute. The database ensures that data are collected so that they can be compared across regions. SEER data from some registries are available since 1973. With the addition of four registries in 2000, there are a total of 16 SEER areas, representing 25% of the United States population of cancer patients, which share common reporting standards so that data can be pooled.[72] Patients with cancer are of interest in end-of-life care because of the more predictable prognosis associated with the disease.[73] SEER data are linked with Medicare claims data using patient identifiers and, after identifiers are removed, are made available for a fee.

Contained within the SEER data are: date of diagnosis, stage and grade at diagnosis, histology of the tumor, surgical or radiation treatment recommended or provided within 4 months of diagnosis, follow-up on vital statistics, cause of death, and patient demographic characteristics. Linkage with Medicare administrative data provides opportunity for longitudinal study designs. These data include information on the use of health services. The linkage of these databases allows analysis of health care utilization before and after diagnosis and prior to death, and provides key information about the stage and grade of the cancer at diagnosis and treatment recommended at the time of diagnosis.[74]

Linkage with the Medicare database limits the population to those 65 and over and those who qualify for Medicare due to disability; however, because the disabled population is so different from the general population, analyses using these data are often limited to those over 65. The benefit of this population is that it is population that is universally insured, reducing (though not eliminating) financial barriers to medical care.

We identified patients diagnosed with lung, gastric and pancreatic cancer between the years 2000 and 2005 from the Patient Entitlement and Diagnosis Summary Files (*PEDSF*) of the SEER-Medicare linkage. These cancers were chosen because of the relatively short survival associated with diagnosis at almost any stage. This increases the chances of observing diagnosis and death from the cancer within the same time period. Three cancers were chosen to assess the variability across cancers and to increase the sample size, particularly among the minority subgroups.

Medicare data provide longitudinal healthcare utilization information and were used to determine hospice use prior to date of death. The population was limited to non-Hispanic white, non-Hispanic black, and Hispanic patients who were diagnosed with cancer after the age of 65 and died as a result of cancer within the follow-up period. Patients were required to have been enrolled in Medicare Parts A and B from diagnosis until death. The cohort was limited to patients for whom this is their first and only cancer. Registries with very low numbers of non-Hispanic black and Hispanic patients during the study period were excluded from our analysis. Other races were not included due to very low numbers in most registries. Patients with an unknown month of diagnosis in the SEER registry were excluded from our analysis because it eliminates the possibility of survival analysis.

Medicare data include information on hospice use in the Hospice Standard Analytic File (SAF). Patients were considered to have used hospice if there was a hospice claim in prior to death. The date of death is identified in the database as the date reported to the Healthcare Financing Administration (HCFA) from the Social Security Administration (SS). Date of death was identified in SEER as well—the level of agreement between SEER and Medicare is generally high and was reported.

Paper 1: Racial disparities in the use of the Medicare Hospice Benefit over time

Introduction

The Medicare Hospice Benefit (MHB) was enacted in the early 1980s, and the number of patients using hospice prior to death has continued to grow dramatically. Approximately 23% of Medicare decedents in 2000 and 43% of Medicare decedents (over 1 million users) in 2010 used hospice.[75] However, many terminally ill people do not take advantage of the MHB, and previous studies have reported that patients' clinical and demographic characteristics are associated with hospice use. Rates of hospice use vary by race, with blacks using hospice less than whites. Patients with lower income and educational attainment,[30,38,41] single people,[76] patients enrolled in fee-for-service payment plans (vs. managed care),[41] and patients residing in rural areas have also been found to have lower rates of hospice use.[38,77] Many of the aforementioned factors are also correlated with minority status, such as lower income and greater likelihood of being unmarried, which adds complexity to understanding the association of race alone.[58,78]

Some of the increase in hospice use is likely due to the diffusion of hospice throughout the population.[34] As the availability and marketing of hospice has increased, this may have led to changes in awareness and acceptance of palliative versus aggressive treatment at the end of life. Also, the hospice setting has changed over time. Hospice is increasingly being provided in settings other than in the patient's home (e.g., inpatient hospices and nursing homes) so patients without family caregivers may take advantage of the benefit. These changes may have led to a decrease in the disparity associated with income, payment type, population density, and marital status.[34]

Part of the increase may be a technical increase in use without much benefit to patients. The proportion of hospice users with very short stays in hospice, whereby a person enrolls less than one week prior to death, has increased over time from 16% in 1990[6] to 31% in 2007.[79] This is concerning because the benefit of hospice is diminished when the patient enters hospice only after death is known to be imminent.[9] Stays greater than 180 days are considered "long use," and again question the benefit of highly specialized care for the dying patient when the patient instead lives so long that they may have achieved greater benefit from rehabilitative care.[9] Patients with cancer, particularly cancers with poor prognoses, are less likely to use hospice for greater than 180 days than patients with noncancer diagnoses, which have a less predictable decline towards death.[80]

Despite overall increases in hospice use, black patients are consistently found to have significantly lower rates of hospice use than white Americans.[31,36,58,78,81] In general, despite lower hospice use, when black cancer patients are enrolled in hospice, they have longer median length of stay than white patients and are less likely to stay less than 7 days.[40,58,82]

Patients with cancer are the prototypical hospice patient and have a relatively predictable decline toward death.[10] Gastric, lung, and pancreatic cancers are associated with poor survival with few effective treatments. Thus, many of these patients are hospice candidates at diagnosis.[83] In our study, we use the Peters-Belson (PB) method to unpack the interaction between race and other factors associated with hospice use over time for this population of known terminal patients. To account for the increase in use attributable to people entering hospice immediately prior to death, we also examine

"quality hospice use," defined as stays between 7 and 180 days, to better understand the previous finding that while blacks use hospice less frequently than whites, they are more likely to have a longer stay in hospice. Using the PB method, we are able to calculate predicted rates of hospice use and quality hospice use for the black population and add to the current literature documenting disparities in hospice use by estimating the unadjusted rates and predicated rates of hospice use by blacks and non-Hispanic whites over time.

Methods

Data

Data from the Surveillance, Epidemiology and End Results (SEER)-Medicare linked database were used to study patients diagnosed with cancer between 1992 and 2007 who subsequently died due to cancer between 1992 and 2008. This database is available from the National Cancer Institute (NCI) and includes information on all incident cases of cancer diagnoses within the geographic areas of the United States that participate in the SEER program. Medicare claims are linked to the SEER cancer information, providing a longitudinal database. This analysis includes patients who resided in the SEER areas that have continuously participated in the program since 1992 and have adequate representation of blacks (at least 5% of the cancer cases)-San Francisco, Connecticut, Detroit, New Mexico, Seattle, Atlanta, San Jose, and Los Angeles.

Population

The study population included non-Hispanic white and black patients aged 65 and older who were diagnosed with regional or distant lung or gastric cancers, or any stage

pancreatic cancer and who died as a result of cancer within the follow-up period. These cancers were chosen because of the relatively short average survival associated with their diagnosis. To observe hospice use after diagnosis, patients were required to have been enrolled in Medicare Parts A and B from diagnosis until death. Because the MHB is billed to CMS, even for managed care patients, patients enrolled in Medicare managed care were included. The cohort is also limited to patients for whom this was the first and only cancer. We excluded patients with an unknown month of diagnosis in the SEER registry and patients who enrolled in hospice prior to the observation period. A figure with exclusions can be found in the appendix. The cohort included men and women with a first primary diagnosis of pancreatic (n=16,955), lung (n=74,979), and gastric (n=7,156) cancer.

Measures

Death in hospice was defined as a hospice claim indicating a discharge status of 'expired' or in which the date of discharge from hospice matches the Medicare date of death. Patients with a discharge status of 'expired' whose Medicare date of death differs by more than 3 days from date of hospice discharge were excluded from the analysis (n=141). Length of stay in hospice was measured from date of hospice enrollment until discharge. Quality hospice stays were defined as stays greater than 7 days and less than 180 days. If someone is discharged from hospice alive, we do include this as a quality stay because our main focus is earlier enrollment in hospice.

We obtained patient's race, and tumor stage (localized, regional, distant) and cause of death from the SEER data. We obtained marital status, sex, age at death, length

of survival after diagnosis, and health maintenance organization (HMO) enrollment (defined as enrollment in HMO during month of death) from Medicare data. Zip code level education (% of population over 25 in zip code with more than high school education) and zip code level median household income were obtained from the SEER-Medicare linkage, which are linked from the 2000 United States Census.

Statistical analysis

Unadjusted rates of hospice use over time for blacks and non-Hispanic whites were examined. Unadjusted rates of hospice and quality hospice use over time for both groups were evaluated using the Cochrane-Armitage test for trend. Differences in rates of hospice use by race during each time period were assessed using the chi-square statistic. Median length of stay was calculated for each year of the time period for both race groups.

The Peters-Belson (PB) method, [7-9] also known as Blinder-Oaxaca method in econometrics, [10-12] has most often been used to understand racial disparities in wages and hiring decisions,[13] but has also been recently used to understand racial disparities in receipt of health services.[14] In our case, the method involves using multivariate logistic regression to model hospice use among non-Hispanic whites using factors known to be associated with hospice use from previous studies and applying estimates obtained from that model to generate predicted probabilities of hospice use among blacks. The measure, in essence, describes the magnitude of the disparity among races that cannot be explained by the factors we have included in the model.

We used the PB method in models predicting hospice use by adjusting for demographic (socioeconomic characteristics of zip code of residence, marital status, age, geographic location, sex, HMO enrollment) and disease factors (stage at diagnosis, survival) which may also account for differential use of hospice among subgroups. Due to our inclusion of patients enrolled in HMO (for whom claims are not available), we are unable to adjust for other case-mix differences. First, we calculated unadjusted rates of hospice use over four year time periods (pooling due to small numbers) from 1992-2008 for blacks and non-Hispanic whites. Next, we fit a logistic regression model estimating association of hospice use among non-Hispanic whites and the following variable: age, sex, area income and educational attainment, marital status, enrollment in fee-for-service payment plans (vs. managed care), cancer diagnoses and geographic location. We applied these individual fitted values from whites to blacks to predict how hospice use would differ among black patients if they were white. The model was run for four time periods 1992-1995, 1996-1999, 2000-2003 and 2004-2008 to assess how the association of race with hospice use changed over time. Standard errors and confidence intervals of the model contribution were calculated using the delta method.[15]

We performed additional analyses to ensure that our conclusions were not sensitive to the choice of years or the exclusion of registries without adequate representation of all groups of interest.

Results

The distribution of members of the black and non-Hispanic white groups differs across most of the demographic factors associated with hospice use (Table 1). Blacks are

younger and are much less likely to be married, and live in zip codes with lower educational attainment and income than non-Hispanic whites in all time periods.

There were significant increases in hospice use from 1992-2008 for both non-Hispanic whites (1992-1995: 36.5% to 2004-2008: 65.5%; $p<.001$) and blacks (1992-1995: 30.8% to 2004-2008: 57.3%, $p<0.001$) (see Figure 1). However, these increases did not result in a decrease in disparity in hospice use, which actually increased from 4.9% to 8.7% (see Table 2).

Figure 1b displays significant increases in quality hospice use from 1992-2008 for non-Hispanic whites (1992-1995: 24.7% to 2004-2008: 40.2%) and blacks (1992-1995: 20.2% to 2004-2008: 35.5%; all trend tests significant at $p<0.001$); however, the increase is smaller than that for any hospice use. The disparity in quality hospice use between blacks and non-Hispanic whites remains significant over time between 4.0 and 5.3%. Most patients who experienced a stay in hospice but did not experience a quality stay in hospice had a stay of less than 7 days (75%; data not shown in table).

Adjusted comparisons between groups require adequate overlap among groups for each of the factors. Table 1 displays the differences between groups and demonstrates that there is adequate representation of each group in the levels of each factor.

Results from the PB analysis of black and non-Hispanic white hospice use are displayed in Table 2. While disparities in hospice use were similar between the 1992-1995 and 2004-2008 time periods (4.9% and 8.7%, respectively), the amount of the disparity explained by the clinical and other demographic characteristics in the base model differed between periods. In the earlier period, 105% of the disparity was

explained by differences in other (non-race) model factors (meaning that if blacks retained all of their characteristics but were white their overall rate of hospice use would be smaller than observed). In the later period, 63.4% of the disparity was explained by the model meaning that 36.6% of the disparity in hospice use was unexplained by model factors. The results contrast to those for quality hospice use, with the model in the earlier period explaining 8.7% of the quality hospice use difference between blacks and whites and 11.1% in the later period. This means that the disparity in quality hospice use remains largely unexplained in both the earlier and later time period.

Repeating the PB analysis in a cohort that comes only from registries where black beneficiaries comprise greater than 5% of the study population yielded importantly similar results. The disparity in hospice use and quality hospice use was similar to the whole population and did not change over time. While the amount of the disparity in hospice use that is explained by the model did not decrease over time when limited to these registries (it instead varied between 57 and 76%), the model could not explain the majority of the disparity in any time period.

Discussion

Our analysis finds significant racial differences in hospice use prior to death for elderly cancer patients in the Medicare population, even after controlling for socioeconomic, demographic, and clinical differences between the groups. Both hospice use and quality hospice stays increased for both races as the number of hospices and hospice users has grown over time. The use by blacks is lower than for whites and is not explained by other racial changes such, income, and location. The increase in use was

greater for quality hospice use for both races. However, racial disparity in quality use was less than overall use in all time periods.

Multivariate logistic regression models with race included as a covariate estimate the average effect of independent variables on the dependent variables regardless of race. We chose the PB method for this analysis because it allows us to estimate the proportion of the disparity in hospice use that is not due to the covariates in the model. For example, in a regression model with race as an independent variable, the association between marital status and hospice use is a weighted average of the association among blacks and whites. In contrast, the PB method estimates the association only for whites. Applying this estimated coefficient to the black population then contributes the difference in use if a black patient retained all their demographic and clinical characteristics (including marital status) but was instead white.

The PB method also does not assume that the effect of race is the same for all individuals. Instead, the disparity remaining after adjustment is estimated for each individual. In this case, the intuition from the PB method did not differ from multivariate logistic regression; there was a significantly smaller odds of blacks using hospice compared to non-Hispanic whites (results available on request) in each time period.

The findings from the PB method show that racial disparity in hospice use remains despite the increase in use by groups with characteristics that correlate with minority status (e.g., lower income, lower education, and non-married). [4,16] Changes in the availability of hospice and the hospice setting have not equalized the disparity.

Instead, although the hospice use of both groups has increased by approximately 50%, the magnitude of the disparity attributed to known factors remains unchanged.

The disparity in hospice use between whites and blacks is not a new finding,[31,36,58,81,82] but we show that it has not changed over time, and that it cannot be accounted for by differences in population demographic and clinical characteristics. In our study population, the difference in quality hospice use among whites and blacks is smaller than the difference in overall hospice use, and only a very small portion of the difference in the earliest and late time periods can be explained by differences in other characteristics.

Hospice utilization prior to death is neither possible nor appropriate for all people. We chose to study patients with cancer because they often experience a trajectory of dying with a predictable decline in the months prior to death that is compatible with earlier entry into hospice.[10] The benefit of the SEER-Medicare database is that it provides information about disease characteristics so that our study population is limited to those who have few curative options making every person essentially eligible for hospice at diagnosis. There is a growing disparity in hospice use between blacks and whites with noncancer diagnoses.[84]

We do not have information regarding whether patients in our study were offered hospice care, despite being eligible. A recent study of patients with metastatic lung cancer found that only half of the patients had a discussion about hospice with a provider within 4 to 7 months of diagnoses, with blacks having lower rates of discussion than non-Hispanic whites.[85] Our data do not include information about whether hospice care was

available where the patient lived. Our measure of quality hospice care is based on length of stay only and does not measure other aspects of hospice quality that may be different over time and across racial groups. Patients can benefit from a short stay in hospice prior to death, but the time for patient and family to spend together after accepting death must be balanced with the stress of transferring care.

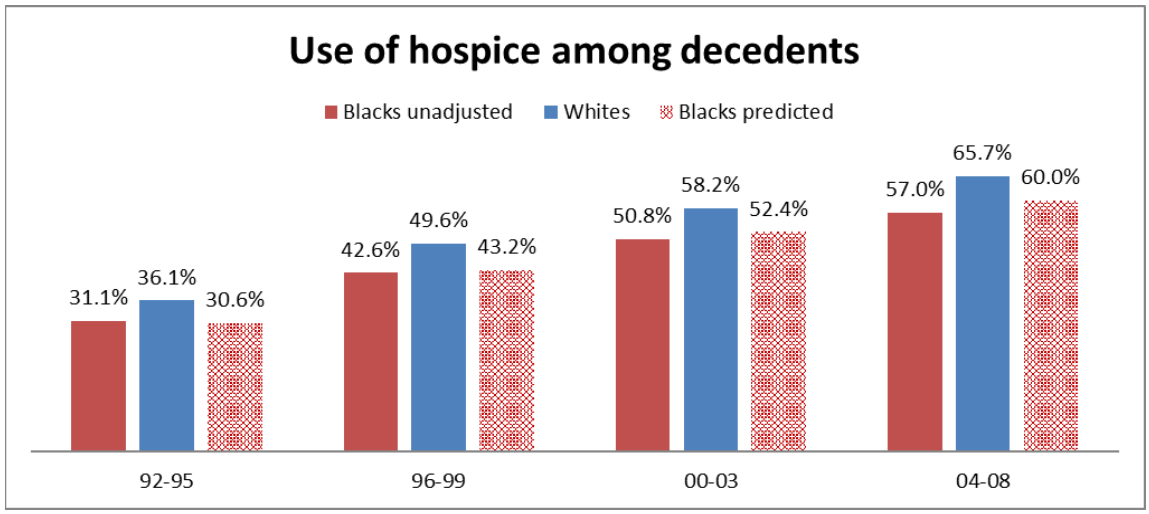
Some studies have reported that blacks are more likely to prefer aggressive care and/or reject hospice care.[36,86] Lack of communication about end of life care[85] and lack of knowledge about the services provided by hospice may be more of a barrier for blacks.[19] There may be important confounding that exists due to lack of access to health care and revealed care preferences,[87] and it is important to note the disparity between blacks and whites in cancer care received is not limited to use of hospice services—it begins at diagnosis.[50,88] It is also possible that hospice is less likely to be available in places where high proportions or minorities reside,[20] and that lower hospice use overall among health centers where blacks are more likely to receive care are is an important contributor.[21] These possibilities deserve further exploration.

We found that while hospice use increased from 1992-2008 for non-Hispanic whites and blacks with cancer, the increase has not lessened disparities in use between these groups. Different patterns were found for quality hospice use versus any hospice use. The increase in quality hospice use for both groups from 1992-2008 is smaller, and the disparity in quality hospice use between blacks and non-Hispanic whites is smaller in all time periods. This suggests that some of the overall increase in hospice use may in fact signal growing use of hospice as a place to die rather than a means of symptom

management and increasing social support prior to death. Further research on how the black experience leads to lower hospice utilization is necessary for policy direction.

Figure 2a and b. Percent of pancreatic, lung and gastric cancer decedents who used hospice (a) and who used "quality" hospice (b) among non-Hispanic whites, blacks, and blacks rates adjusted as if they used hospice similar to whites, 1992-2008

a)



b)

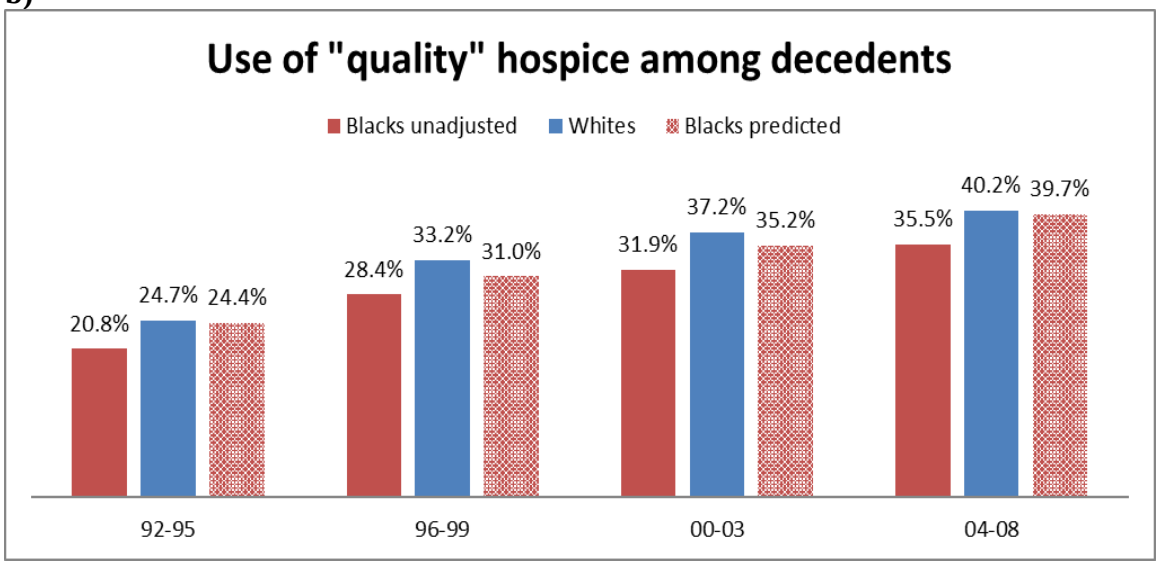


Table 2. Characteristics of lung, pancreatic and gastric cancer decedents from the SEER-Medicare data, 1992-2008, by race.

		92-95		96-99		00-03		04-08	
		white	black	white	black	white	black	white	black
		overall	overall	overall	overall	overall	overall	overall	overall
Total	99,090	19,582	2,040	22,861	2,321	23,227	2,514	23,878	2,667
Age (years)	65-69	21.9%	26.1%	18.7%	23.1%	16.3%	22.8%	16.2%	21.1%
	70-74	27.7%	29.9%	26.9%	29.3%	25.4%	26.6%	23.3%	25.6%
	75-79	23.7%	22.6%	24.7%	22.1%	25.7%	24.6%	24.7%	23.5%
	80-84	15.8%	12.6%	17.7%	14.6%	18.9%	14.5%	20.3%	17.1%
	85+	10.9%	8.9%	11.9%	10.9%	13.7%	11.5%	15.4%	12.7%
Sex	Male	56.0%	60.2%	53.0%	54.5%	52.0%	50.6%	50.5%	48.3%
	Female	44.0%	39.8%	47.0%	45.5%	48.0%	49.4%	49.5%	51.7%
Registry	CT	17.5%	6.6%	18.4%	8.6%	17.2%	8.2%	17.5%	8.5%
	Detroit	16.7%	43.3%	16.9%	45.7%	16.3%	39.6%	16.7%	38.3%
	Seattle	15.8%	3.6%	17.1%	4.3%	17.2%	4.8%	17.6%	4.3%
	Atlanta/ Georgia	5.9%	18.1%	6.0%	17.9%	5.9%	20.6%	5.9%	21.4%
	California	17.7%	25.1%	15.0%	20.3%	16.5%	23.4%	15.1%	23.9%
	Other*	26.4%	3.3%	26.6%	3.2%	9.9%	3.4%	27.3%	3.6%
Medicare	FFS	88.6%	88.9%	81.6%	81.7%	79.2%	78.8%	81.9%	79.9%
	HMO	11.4%	11.1%	18.4%	18.3%	20.8%	21.2%	18.1%	20.1%
Marital Status	Single	5.8%	11.9%	6.3%	15.8%	6.5%	16.0%	6.5%	17.4%
	Married	53.8%	40.5%	53.0%	37.9%	51.4%	34.2%	50.8%	31.1%
	Previously Married	37.9%	44.6%	38.3%	42.2%	39.7%	45.8%	39.3%	47.9%
	Unknown	2.4%	3.0%	2.5%	4.1%	2.5%	4.0%	3.4%	3.6%
Quartile Education	Q1	21.4%	50.9%	21.0%	48.6%	20.0%	46.1%	19.3%	43.1%
	Q2	23.6%	25.3%	23.8%	25.3%	24.2%	27.2%	23.7%	28.0%
	Q3	24.6%	15.0%	24.6%	17.0%	25.3%	17.2%	26.3%	19.2%
	Q4	25.8%	5.4%	26.4%	5.4%	26.8%	6.2%	26.2%	5.8%
	Unknown	4.5%	3.3%	4.2%	3.7%	3.8%	3.2%	4.6%	3.9%
Quartile Income	Q1	21.2%	71.7%	19.9%	67.6%	18.3%	63.8%	17.3%	60.8%
	Q2	25.2%	16.0%	24.0%	17.4%	24.4%	20.1%	23.2%	21.2%
	Q3	25.0%	5.9%	25.9%	7.2%	26.2%	8.4%	26.6%	9.4%
	Q4	24.0%	3.1%	26.1%	4.0%	27.3%	4.4%	28.3%	4.7%
	Unknown	4.5%	3.3%	4.2%	3.7%	3.8%	3.2%	4.6%	3.9%
Cancer	Pancreatic	16.8%	19.4%	16.6%	18.4%	16.7%	17.4%	17.6%	20.2%
	Lung	75.4%	69.3%	76.0%	70.7%	76.7%	72.4%	76.4%	71.3%
	Gastric	7.8%	11.3%	7.4%	10.9%	6.6%	10.1%	6.1%	8.5%
Stage	Regional	23.6%	23.5%	26.8%	26.5%	28.1%	26.5%	26.3%	24.1%
	Distant	60.7%	63.0%	58.8%	59.2%	61.8%	64.2%	65.7%	69.6%
	Unknown	15.7%	13.4%	14.4%	14.2%	10.0%	9.3%	8.0%	6.3%

*Other SEER registry=Utah, Iowa, New Mexico and Hawaii

Table 3. Peters Belson estimates of the disparity in hospice use between black and non-Hispanic white pancreatic, lung and gastric cancer decedents

	1992-1995	1996-1999	2000-2003	2004-2008
Hospice Use				
Whites	36.1%	49.6%	58.2%	65.7%
Blacks unadjusted	31.1%	42.6%	50.8%	57.0%
Blacks predicted	30.8%	43.1%	52.4%	60.2%
Unadjusted disparity	4.9%	7.0%	7.4%	8.7%
Percent of disparity explained (se)	105.6% (1.1%)	92.7% (0.6%)	78.3% (0.6%)	63.4% (0.8%)
Quality Hospice Use				
Whites	24.7%	33.2%	37.2%	40.2%
Blacks unadjusted	20.8%	28.4%	31.9%	35.5%
Blacks predicted	24.4%	31.0%	35.2%	39.7%
Unadjusted disparity	4.0%	4.8%	5.3%	4.8%
Percent of disparity explained (se)	8.7% (1.6%)	47.0% (0.6%)	36.4% (0.6%)	11.1% (0.8%)

Paper 2: Treatment intensity and use of hospice: Is hospice only for those who opt out of aggressive cancer treatment?

Introduction

Hospice is a team approach to pain and symptom management of a terminally ill patient that includes psychological, social and spiritual care of patients and their families. Since 1983, the Medicare program has covered hospice care with very specific conditions of participation—the patient must have a physician certify a prognosis of less than 6 months to death, the patient must agree to accept that Medicare will not cover any curative treatment, and the care must be provided by Medicare certified hospices. The hospices are paid under a capitated payment system that emphasizes informal care of the patient in the home with hospice staff supplementing that care.[18]

The Medicare Hospice Benefit (MHB) was explicitly offered as an alternative to curative care. Medicare will not pay for curative care after a patient is enrolled in the MHB unless the MHB is revoked by the patient. A patient entering hospice, therefore, must accept a terminal prognosis and not rely on treatments for life extension.[89] Perhaps because of this, the conventional wisdom is that patients who choose hospice prefer less aggressive treatment, as evidenced by concerns about selection bias in studies of care at the end of life because hospice users would not have used aggressive care even in the absence of hospice care.[90,91] However, a patient need not enter hospice immediately upon receiving a poor prognosis. A number of treatments may be tried prior to entering hospice; in fact, this may be necessary for the patient and provider to accept that death is inevitable.

Few studies have focused explicitly on the link between receipt of curative or life extending treatment given prior to hospice entry. Most studies of hospice use have focused on describing whether hospice care was utilized prior to death and the length of stay in hospice.[31,40,92] Results of such studies have revealed systematic variation in hospice use by age, race, marital status, geographic location, type of treating physician, and other non-medical factors. Paradoxically, many of the factors associated with a lower likelihood of using hospice are also associated with lower likelihood of receiving aggressive treatment (e.g., race and older age).[48–50,93] Also, studies measuring medical costs prior to death have found that hospice users have higher medical costs than non-hospice users. For example, Miller et al. studied nursing home residents and found that in the year prior to death (with a substantial amount of that time prior to hospice entry) mean expenditures were higher among the hospice users than the non-hospice users.[64]

We hypothesize that patients receiving fewer aggressive and potentially curative treatments will use hospice less than patients who do not receive these potentially curative treatments. Lung cancer comprises an estimated quarter of all cancer deaths in 2012.[83] We focus on patients diagnosed with American Joint Committee on Cancer (AJCC) stage IIIa non-small cell lung cancer (NSCLC), and all stage IIIb NSCLC because these patients face poor prognoses (5 year relative survival: 24% for stage IIIA and <5% for stage IIIb) (internal SEER analysis) as well as plausible life extending treatment options. Our study provides an opportunity to examine hospice use among patients who have choices about whether to pursue life extending or palliative approaches to their cancer care.

Methods

We received approval from the University of Minnesota Institutional Review Board (IRB) and SEER-Medicare program at the National Cancer Institute (NCI) to undertake this research project.

We used the Surveillance, Epidemiology and End-Results (SEER)-Medicare linked database for this analysis. The SEER data arise from a collection of population based tumor registries headed by the NCI. The SEER database contains uniformly collected data for analysis across registries. With the addition of four registries in 2000, there are a total of 16 SEER areas, representing 25% of the United States population with cancer. The SEER data contain date of diagnosis, stage and grade at diagnosis, histology of the tumor, initial surgical or radiation treatment recommended or provided, follow-up on vital statistics, cause of death, and patient demographic characteristics. Linkage with Medicare administrative data allows analysis of health care utilization before and after diagnosis and prior to death, with SEER data providing key information about the stage and grade of the cancer at diagnosis and treatment recommended at the time of diagnosis.[74]

We limited our cohort to elderly patients residing in SEER areas who were diagnosed with stage III NSCLC between 2000 and 2006. We excluded those people who were unlikely to have complete claims (those ever enrolled in Medicare managed care or who were not enrolled in both Medicare Parts A and B) for the duration of the study. We followed people from 12 months prior to diagnosis (to understand underlying comorbidities) until death or the end of 2007. We did not include patients who were

diagnosed in Louisiana in 2005 due to the disruption to the SEER registry caused by Hurricane Katrina. We excluded patients who were diagnosed with any other cancer prior to or after their lung cancer diagnosis to ensure that: 1) a uniform population was followed and 2) cancer treatments were given for lung cancer. (See appendix for complete cohort ascertainment).

We used Medicare billing codes to document surgical treatment (resection), radiation therapy and chemotherapy received by the patient following diagnosis (see appendix for billing codes used). We followed the approach outlined by Davidoff et al. (2010) to determine whether patients likely received a single course of chemotherapy or multiple courses.[94] Briefly, we defined a course as any agent initiated within 29 days of the start of a course of chemotherapy. Initiation of a second agent after 29 days or after a 45 day period without claims was considered a second chemotherapy treatment. We summarized the treatments received as the count of treatments, and receiving two distinct courses of chemotherapy counted as two treatments. For example, we considered a patient receiving radiotherapy and two courses of chemotherapy to have received three treatments (Table 1).

We controlled for factors associated with the use of hospice other than treatment: sex (reported by Medicare), race and ethnicity (reported by SEER), stage at diagnosis (IIIa vs. IIIb), age at diagnosis, and registry. We also measured comorbidities in the 12 months prior to diagnosis using the Charlson score method described by Klabunde et al. (1999).[95]

The primary outcomes of interest are use of hospice prior to death and length of

stay in hospice among hospice users. We defined use of hospice as one or more claims for hospice care after diagnosis and prior to death. We examined diagnosis codes for hospice and found that 92% had a diagnosis of lung cancer or other respiratory diagnosis on at least one hospice claim. We excluded patients (<1%) who appeared to have used hospice prior to the lung cancer diagnosis in the claims because they may have had another serious illness for which they received our treatments of interest. We determined length of time in hospice using the time from the hospice start date to the Medicare date of death (obtained from social security records).

We used the first date of cancer diagnosis in the Medicare claims as the diagnosis date. This diagnosis date matched the SEER month of diagnosis in 80% of the cases, and was within one month for an additional 10% of cases. Time from diagnosis to hospice use was determined by measuring the number of months from the diagnosis date to the start date on the first hospice claim.

We also measured months of survival after diagnosis. Overall survival was measured as death from any cause, and cancer-specific survival measured deaths attributed to cancer on the death certificate.

Analysis

We measured the bivariate association of treatment use with demographic and clinical characteristics using the chi-square test to detect statistically significant differences.

We used Kaplan-Meier survival curves to describe the relationship of treatment use and survival (overall and cancer specific), time to initiation of hospice and, among

hospice users, time in hospice. For overall survival, we censored individuals at the end of the observation period. For cancer-specific survival, we censored individuals at non-cancer death or alive at the end of the observation period. We censored individuals at date of death (for non-hospice users only) or the end of the observation period when measuring time to hospice use and time in hospice.

We examined the association of aggressive treatment with hospice use after adjusting for known confounders (age, race, sex, registry, stage, and comorbidities) using multivariate logistic regression. This analysis included only patients who died during the observation period.

We used multivariate Cox proportional hazards models to estimate the association of treatment with the hazard of dying and of using hospice after adjusting for known confounders. Among hospice users, a multivariate Cox proportional hazards model was used to estimate the association of treatment with the length of enrollment in hospice. We censored observations as described above.

Sensitivity analysis

As a sensitivity analysis, we excluded patients from the analysis of 'time in hospice' if their date of discharge did not match the date of death (2.4% of cases). We also determined if results would change if the SEER diagnosis month and year were used (with the 15th of the month as the proxy day). Our findings did not change in either case.

Results

We identified 9,400 patients older than 66 who were diagnosed with stage IIIA or IIIB NSCLC in SEER between 2000 and 2006 (excluding pleural effusion). Three

quarters (n=7,154) died before the end of 2007. Median cancer-specific survival was 12 months among patients with stage IIIA disease and 9 months among patients with stage IIIB disease. Patients were evenly distributed among the treatment groups: 25% received no treatment, 25% received one treatment, 22.5% received 2 treatments, and 27.2% received 3 treatments. Radiation was the most common single treatment received at 16.8%, a combination of radiation and chemotherapy was the most common in the two treatment group at 16.0% and the most common three treatment combination was radiotherapy and two rounds of chemotherapy (18.6%). The amount of treatment received varied by age, race, stage, registry, comorbidity score and year of diagnosis (all $p<0.05$, Table 2). Hospice use did not vary significantly by treatment level ($p=0.11$).

Cancer-specific survival

Analyses with either unadjusted Kaplan-Meier and multivariate cox models indicated that patients who used more treatments survived longer (Figure 1). The median cancer-specific survival among patients varied by amount of treatment for patients with: no treatment, 4 months; one treatment, 8 months; two treatments, 11 months; and three treatments, 21 months (log rank p-value: <0.0001). The multivariate Cox proportional hazards model found that patients who received no treatments had an increased hazard ratio of mortality of 3.4 (chi-square p-value <0.0001) compared with patients receiving three treatments (Table 2). Increasing age and comorbidity score and diagnosis in earlier years were also associated with significantly shorter time to death, while Hispanic white and Asian/Pacific Islander had significantly longer time to death compared to non-Hispanic whites (Table 2).

Hospice use

Among patients who died of cancer prior to 2008, receiving fewer treatments was not associated with a significant difference in the propensity to use hospice with the exception of patients using two treatments who were significantly less likely to use hospice than patients receiving three treatments (OR: 0.835, p=0.012; Table 4). Factors associated with propensity to use hospice were age over 75 years (vs. <70), female sex, and diagnosis in later years (Table 4).

While the number of treatment types did not predict hospice use, the number of treatment types was significantly related to time to enter hospice. Predicting time to hospice found that patients receiving fewer treatment types had a much shorter time from diagnosis to hospice compared to patients receiving three or more treatments (HR: 3.85, p-value <0.0001; Table 3).

Among hospice users, the amount of time spent in hospice varied with the amount of treatment received prior to hospice entry (log rank p=<0.0001, Figure 2). Patients who had no treatment had the longest median time in hospice (28 days), while patients who had 3 or more treatment had the shortest median time in hospice (16 days). Patients who used 0, 1, and 2 treatments experienced a longer stay in hospice compared to patients with three or more treatments (HR: 0.759, p<0.0001, HR: 0.874, p=0.003, and HR: 0.886, p=0.01, respectively, Table 5). While very short stays (less than three days) were common, patients with 3 or more treatments were most likely to experience a stay of less than three days (3 treatments, 31.1%; two treatments, 19.3%; one treatment, 24.3%; and no treatments: 25.3%; chi-square p-value <0.0001, data not shown in table).

Discussion

In our analysis, we found that patients who received more treatment were as likely to use hospice as patients receiving less or no treatment; however, patients with more treatment did experience significantly shorter stays in hospice and had a longer time to hospice enrollment after diagnosis. Our population based findings mirror a recent single institution study examining resource use at the end of life among patients with advanced lung cancer which found that while 65% of patients used hospice prior to death, length of stay in hospice was short and many patients (40%) were receiving anticancer therapy within 30 days of death.[96]

One of the purposes of the MHB when enacted was to reduce costs associated with end of life care by substituting palliative care in the home for intensive treatment and crisis symptom relief. In our analysis, 46% of hospice patients who used hospice also received more than two anti-cancer treatments prior to hospice entry. In these cases, hospice use complements anticancer therapy rather than providing a substitute. While we have not included costs in this analysis, intensive use of treatment prior to hospice has cost implications. Studies of cost savings from hospice have been inconclusive;[62,64,90,91] this may be attributed, in part, to the time window chosen—if patients who use hospice also use expensive treatments prior to hospice entry, any window including this time period may find that hospice patients are more expensive due to use of both life extending therapy and palliative care.[62]

Due to the benefits of hospice,[2] concerns have arisen about patients who do not access the benefit because they want to purse life extending treatment.[36] Some have

advocated for reform of end of life care that embraces the combination of anti-cancer therapy and palliative care. Open access hospice or initiating palliative medicine consultation beginning at diagnosis are two common suggestions.[97] In the open access hospice model, curative treatment need not be abandoned before enrolling in hospice care. Consultation with a palliative medicine specialist provides the patient with an expert to evaluate pain and symptom management as well as psychosocial needs while curative treatment is received. A recent small study found that when enrolled in early palliative care, patients experienced longer length of stay in hospice and were less likely to have received chemotherapy within 60 days of death but were not less likely to receive anticancer treatments overall.[98]

It seems possible that some patients in our analysis who chose life-extending treatments did not have the chance to benefit from hospice because they died while receiving treatment. Reforms would allow these patients to benefit from palliative services. The open access hospice model or early initiation of palliative care may not save money by avoiding intensive treatment; however, both models may prevent expensive hospitalizations for managing symptoms associated with the dying process as well as providing psychosocial support to the patient and family.

Whether or not the hospice program is changed to allow for the receipt of curative treatment, seriously ill patients should receive information about hospice, regardless of their current treatment choices as we have shown that patients receiving life-extending treatment need not be opposed to hospice use. Providing information about hospice early, with the understanding that patients are not ready for the benefit but may become

so in the future may help to increase the length of stay in hospice since patients with short stays are unlikely to experience the full benefit of hospice.[99]

The strengths of this analysis lie in the prospective design, the selection of a population for whom therapy may provide some survival benefit but declining treatment is equally rational, and use of the population-based data. However, this is an analysis of administrative data, and only information collected for the purposes of Medicare billing and cancer registration are available to our analysis. There is no information about the treatment options offered to patients, particularly when or if patients are offered hospice. In addition, it is impossible to know whether patients who received more treatment survived longer because of their treatments or used more treatment because they survived longer. Thus, this work should not be seen as evidence that aggressive treatment for patients with stages IIIa and IIIb NSCLC improves survival.

Our analysis finds that patients who opt to receive rigorous life-extending treatments are as likely to use hospice as those who choose no treatment. It may be time to change the view of hospice as a substitute for curative or life-extending treatment to that of hospice as a complement to life-extending treatment. Changing our approach may lend more coherence to payment policy reform and allow for a focus on the goals of care rather than the care itself.

Table 4. Treatments used in each treatment category

		N	%
No treatment		**2372**	**25.2**
1 Treatment		**2354**	**25.0**
	Chemotherapy	366	3.9
	Radiation	1578	16.8
	Surgery	410	4.4
2 Treatment		**2119**	**22.5**
	Chemotherapy (2 rounds)	268	2.9
	Chemotherapy+Radiation	1507	16.0
	Surgery+Radiation	230	2.5
	Surgery+Chemotherapy	114	1.2
3 Treatments		**2555**	**27.2**
	Surgery+Chemotherapy+Radiation	693	7.4
	Surgery+Chemotherapy(2)	110	1.2
	Radiation+Chemotherapy(2)	1752	18.6

Table 5. Population characteristics by treatment type, including hospice use

Number of Treatments		0	1	2	3	**p-value**
Total		**2,372**	**2,354**	**2,119**	**2,555**	
% who died before 2008		82.5%	78.4%	76.4%	67.8%	
Hospice use among decedents		56.8%	57.7%	54.1%	57.8%	0.1057
Age (years)	66-69	15.5%	13.5%	23.7%	30.0%	<0.0001
	70-74	23.1%	24.1%	32.6%	36.2%	
	75-80	26.1%	29.6%	27.3%	22.9%	
	80+	35.3%	32.8%	16.5%	11.0%	
Race	Non-Hispanic white	80.6%	82.4%	85.2%	85.6%	<0.0001
	Black	11.1%	9.6%	7.1%	6.8%	
	Hispanic	4.6%	4.0%	3.4%	3.5%	
	Asian/Pacific Islander	3.3%	3.8%	3.7%	3.9%	
Sex	Male	57.6%	52.8%	55.8%	55.7%	0.011
	Female	42.4%	47.2%	44.2%	44.3%	
Stage	Stage IIIa	54.1%	56.3%	53.6%	59.6%	<0.0001
	Stage IIIB	45.9%	43.7%	46.4%	40.4%	
Charlson score	0	40.5%	38.2%	44.9%	49.4%	<0.0001
	1	27.7%	31.3%	33.5%	32.4%	
	2+	31.8%	30.5%	21.6%	18.1%	
Registry	San Francisco	4.0%	3.1%	2.2%	2.8%	<0.0001
	Connecticut	5.8%	8.0%	7.0%	8.6%	
	Detroit	8.1%	7.6%	8.7%	9.2%	
	Hawaii	1.6%	1.6%	1.6%	1.8%	
	Iowa	5.0%	6.7%	7.1%	7.3%	
	New Mexico	2.1%	1.7%	1.9%	1.3%	
	Seattle	7.1%	4.8%	6.1%	5.5%	
	Utah	1.4%	1.0%	1.5%	0.9%	
	Atlanta	3.4%	2.5%	3.2%	3.0%	
	San Jose	1.1%	2.0%	2.1%	2.2%	
	Los Angeles	4.8%	4.7%	5.5%	5.2%	
	Greater California	19.7%	16.0%	15.4%	18.3%	
	Kentucky	13.7%	12.5%	12.6%	11.7%	
	Louisiana	8.5%	11.3%	8.8%	7.3%	
	New Jersey	13.1%	16.1%	15.8%	14.5%	
Year of death	2000	11.8%	15.0%	13.7%	11.9%	<0.0001
	2001	14.5%	15.7%	14.0%	12.1%	
	2002	14.9%	14.8%	15.6%	12.0%	
	2003	16.1%	15.5%	15.4%	15.5%	
	2004	14.7%	14.4%	14.3%	17.2%	
	2005	14.8%	12.7%	14.1%	14.9%	
	2006	13.2%	11.9%	12.8%	16.5%	
Marital Status	Never Married	8.5%	7.2%	6.0%	5.6%	<0.0001
	Married	41.8%	44.6%	54.6%	59.8%	
	Previously Married	44.9%	43.7%	35.5%	31.3%	
	Unknown	4.6%	4.5%	3.9%	3.4%	
Zip code median income	Q1	27.5%	24.3%	23.0%	20.9%	<0.0001
	Q2	24.7%	24.3%	23.1%	23.5%	
	Q3	22.9%	23.4%	25.6%	24.6%	
	Q4	20.5%	24.0%	23.9%	26.5%	
	Unknown	14.5%	15.7%	14.0%	12.1%	

Table 6. Multivariate cox proportional hazards models* predicting cancer specific mortality and time to hospice use

		Cancer specific mortality				*Time to hospice*			
		Hazard Ratio	95% Confidence Interval		p-value	Hazard Ratio	95% Confidence Interval		p-value
Treatments	0	3.363	3.139	3.603	<.0001	3.822	3.501	4.173	<.0001
	1	1.919	1.792	2.056	<.0001	1.855	1.698	2.025	<.0001
	2	1.537	1.435	1.646	<.0001	1.464	1.34	1.6	<.0001
	3	1.0				1.0			
Age	66-69	1.0				1.0			
	70-74	1.106	1.032	1.184	0.0041	1.1	1.004	1.205	0.0413
	75-80	1.249	1.164	1.341	<.0001	1.406	1.282	1.542	<.0001
	80+	1.328	1.234	1.43	<.0001	1.681	1.53	1.848	<.0001
Race	Non-Hispanic white	1.0				1.0			
	Black	0.989	0.905	1.079	0.7975	0.981	0.875	1.1	0.7451
	Hispanic	0.862	0.761	0.977	0.0199	0.909	0.773	1.068	0.2446
	Asian/Pacific Islander	0.781	0.671	0.909	0.0014	0.644	0.518	0.801	<.0001
Sex	Male	1.0							
	Female	0.853	0.81	0.897	<.0001	1.003	0.94	1.07	0.9277
Stage	Stage IIIa	0.721	0.688	0.756	<.0001	0.727	0.684	0.772	<.0001
	Stage IIIB	1.0				1.0			
Charlson	0	1.0				1.0			
	1	1.132	1.072	1.196	<.0001	1.159	1.081	1.244	<.0001
	2	1.204	1.134	1.278	<.0001	1.234	1.143	1.332	<.0001
Marital Status	Never Married	1.0				1.0			
	Married	1.05	0.953	1.157	0.3224	0.909	0.793	1.042	0.909
	Previously Married	1.046	0.991	1.104	0.0995	1.127	1.053	1.207	1.127
	Unknown	0.974	0.86	1.102	0.6732	0.973	0.827	1.144	0.973
Zip code median income	Q1	1.0				1.0			
	Q2	0.979	0.915	1.048	0.5427	0.922	1.103	0.8566	0.922
	Q3	0.937	0.875	1.004	0.0636	0.964	1.151	0.2526	0.964
	Q4	0.902	0.842	0.967	0.0038	0.953	1.139	0.3665	0.953
	Unknown	0.905	0.797	1.027	0.1207	0.892	1.227	0.5808	0.892

*Models included SEER registry and diagnosis year; observations are censored at non-cancer death and end of the observation period.

Table 7. Logistic regression predicting hospice use among lung cancer decedents

		Odds Ratio	95% Confidence Interval		p-value
Treatments	0	0.892	0.775	1.026	0.0992
	1	0.915	0.794	1.053	
	2	0.838	0.728	0.965	
	3	1.0			
Age	66-69	1.0			<0.0001
	70-74	0.933	0.811	1.073	
	75-80	1.169	1.012	1.35	
	80+	1.433	1.231	1.667	
Race	Non-Hispanic white	1.0			0.0610
	Black	1.067	0.891	1.277	
	Hispanic White	1.051	0.814	1.357	
	Asian/Pacific Islander	0.671	0.492	0.913	
Sex	Male	1.0			<0.0001
	Female	0.714	0.644	0.793	
Stage	Stage IIIa	1.075	0.976	1.184	0.1447
	Stage IIIB	1.0			
Charlson Score	0	1.0			0.7054
	1	0.98	0.875	1.097	
	2+	0.949	0.84	1.073	
Diagnosis year	2000	1.0			0.0034
	2001	1.053	0.883	1.257	
	2002	1.273	1.064	1.522	
	2003	1.059	0.889	1.262	
	2004	1.284	1.072	1.537	
	2005	1.334	1.107	1.606	
	2006	1.247	1.023	1.521	
Marital Status	Never Married	1.0			**<0.0001**
	Married	0.683	0.56	0.834	
	Previously Married	1.146	1.025	1.281	
	Unknown	0.932	0.724	1.2	
Zip code median income	Q1	1.0		1.0	**0.0003**
	Q2	1.064	0.926	1.222	
	Q3	1.222	1.062	1.407	
	Q4	1.357	1.176	1.566	
	Unknown	1.126	0.869	1.458	

*Model included SEER registry.

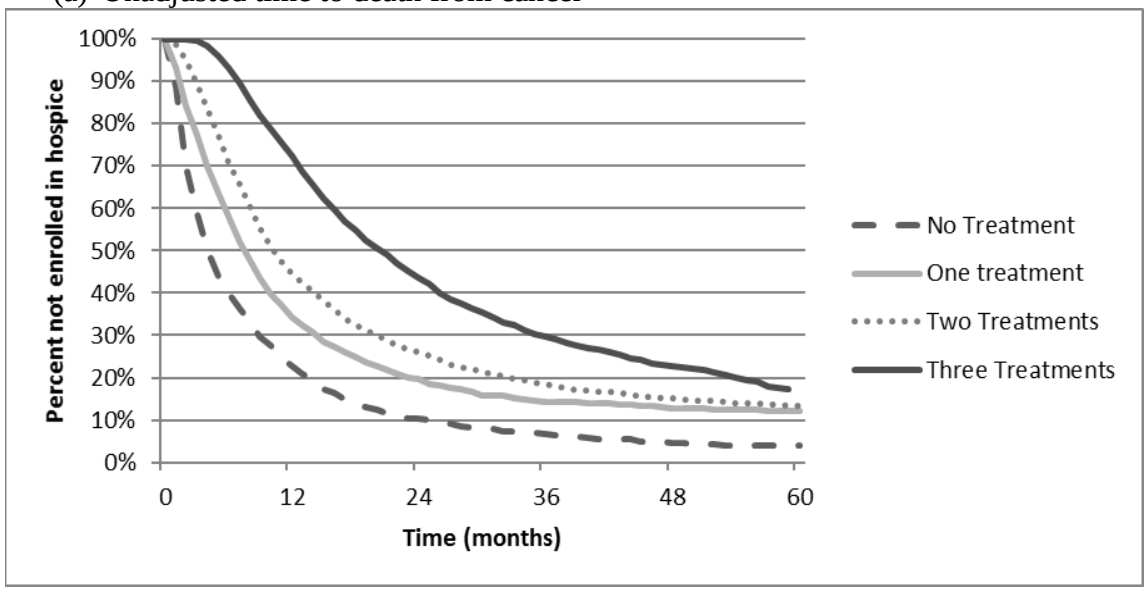
Table 8. Mutivariate Cox proportional hazards model predicting mortality after hospice entry

		Hazard Ratio	95% Confidence Interval		p-value
Treatments	0	0.775	0.708	0.849	<.0001
	1	0.888	0.812	0.972	
	2	0.891	0.812	0.977	
	3	1.0			
Age	66-69	1.0			0.2639
	70-74	0.924	0.84	1.016	
	75-80	0.952	0.866	1.047	
	80+	0.914	0.83	1.007	
Race	Non-Hispanic white	1.0			0.1575
	Black	1.033	0.915	1.166	
	Hispanic White	0.848	0.714	1.006	
	Asian/Pacific Islander	0.871	0.695	1.092	
Sex	Male	1.0			0.0002
	Female	0.88	0.822	0.942	
Stage	Stage IIIa	0.979	0.92	1.043	0.5134
	Stage IIIB	1.0			
Charlson	0	1.0			0.6706
	1	1.013	0.942	1.09	
	2+	1.037	0.957	1.124	
Marital Status	Never Married	1.0			0.0421
	Married	0.912	0.789	1.053	
	Previously Married	0.922	0.858	0.99	
	Unknown	0.837	0.707	0.991	
Zip code median income	Q1	1.0 (ref)			0.2224
	Q2	1.011	0.92	1.11	
	Q3	1.033	0.942	1.133	
	Q4	1.047	0.953	1.149	
	Unknown	0.858	0.722	1.019	

*Models included SEER registry and diagnosis year; observations are censored at non-cancer death and end of the observation period; this model only includes hospice users.

Figure 3. Kaplan-Meier curves depicting time from diagnosis to death from cancer (a) and time from diagnosis to hospice entry (b) among all Medicare beneficiaries with stage III lung cancer, by number of treatments

(a) Unadjusted time to death from cancer



(b) Unadjusted time to hospice by treatment

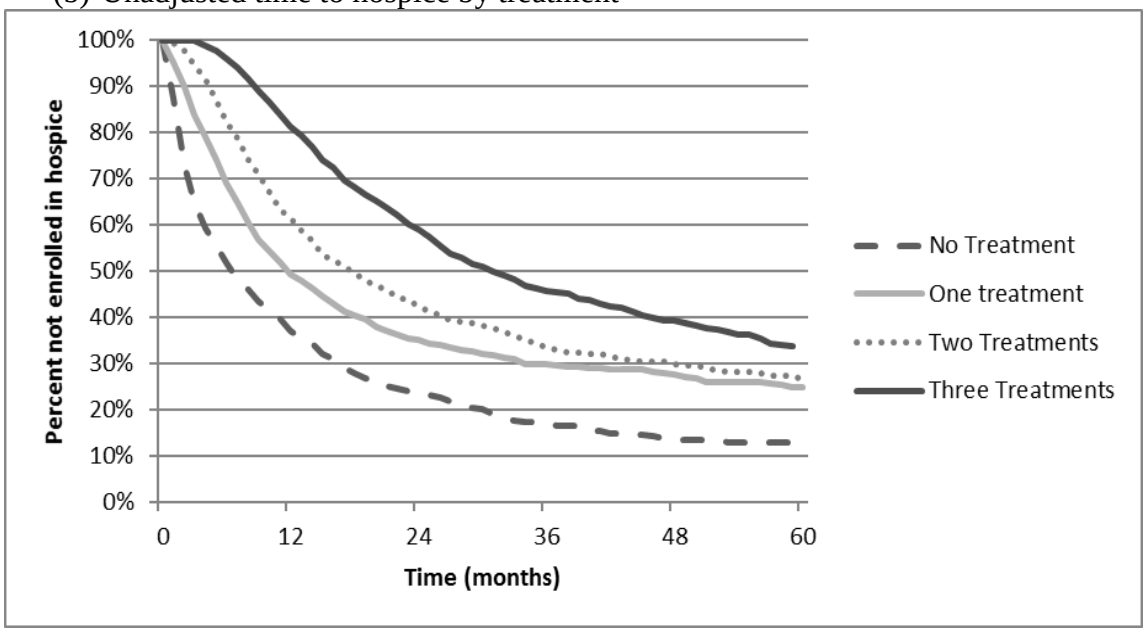
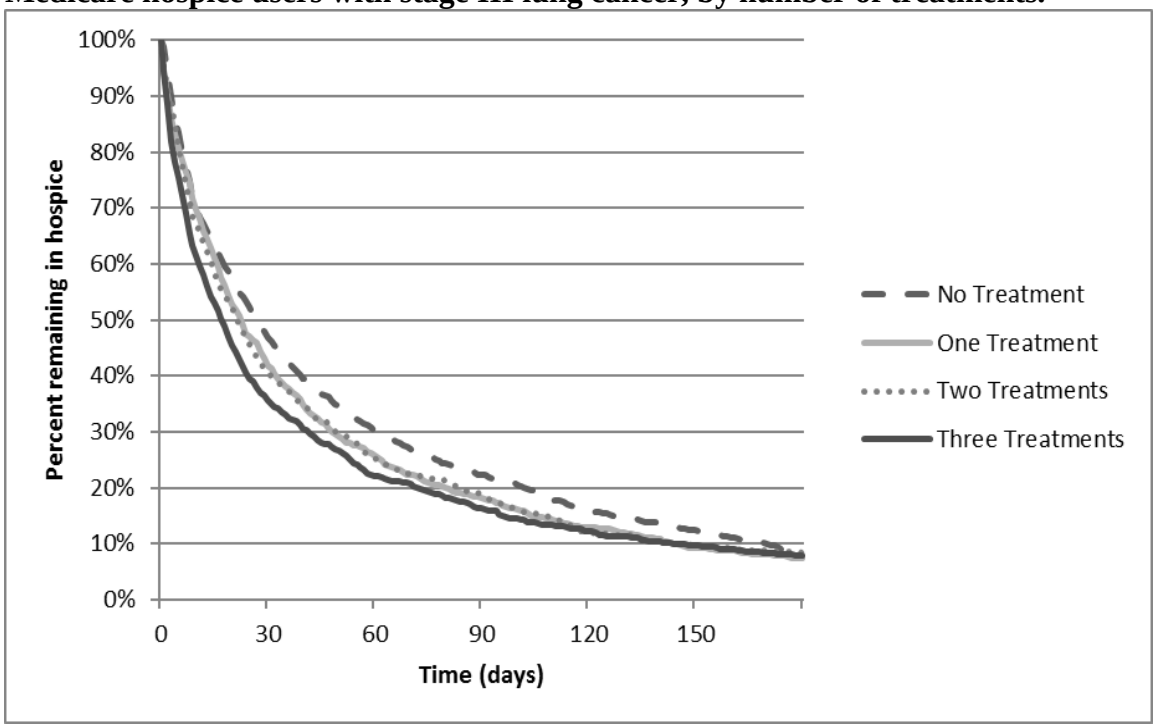


Figure 4. Kaplan-Meier curves depicting time from hospice entry to death among Medicare hospice users with stage III lung cancer, by number of treatments.



Paper 3: Place of death in terminal cancer: does hospice mean death at home?

Introduction

Hospice was introduced to the United States in the 1970's as an alternative way of caring for dying patients, particularly as an alternative to institutionalized death. Improvements in medical technology enabled doctors to prolong life for patients, which often meant that death occurred within the walls of a hospital while under the care of a physician. The first hospices provided care in small home-like hospice buildings separate from hospitals or in patient's homes and focused on both physical and psychosocial care giving for the patient and family. While life-prolonging care in an institution was costly physically, emotionally, and financially, the focus of hospice was quality of life in the face of impending death.[11,89,100] Hospices were originally developed with diagnoses like cancer in mind, whereby a patient experienced a relatively predictable decline towards death.[10]

When the Medicare Hospice Benefit (MHB) was first introduced in the Tax Equity, Fairness and Responsibility Act of 1982 (TEFRA), it proposed dual purposes of cost containment and improving the quality of life for Medicare beneficiaries who were dying. Central to both of these purposes was the idea that hospice services would primarily be delivered in patients' homes, where the patient would be surrounded by a familiar environment and family members. The MHB's payment design favors home care and TEFRA included a limitation of a hospice provider's total inpatient care days to 20 percent of all care days provided by the hospice during the year.[17]

Given this history, it is not surprising that to hear the word "hospice" is to think of a patient dying at home. However, use of hospice has changed a great deal since the MHB

was enacted in 1983; the number and type of hospices as well as the way they provide care has grown in tandem with large increases in the number of Medicare beneficiaries electing hospice.

The purpose of our analysis is to answer the question, "Is the MHB a home-based benefit?" Previous analyses that have addressed the question of location of death among patients enrolled in hospice have done so within the context of a single hospice provider or small number of hospices.[99,101,102] In 2007, Medicare began collecting information on the location of service (LOS)[103] to better understand trends in utilization of the MHB, allowing us to answer the question on a much larger scale. We use this information to study some of the prototypical home hospice users—cancer patients--to understand which groups die at home and to examine the relationship between location of death and length of stay.

Methods

Our analysis was approved by the University of Minnesota Institutional Review Board.

The SEER-Medicare linked data combines information collected from the population-based Surveillance, Epidemiology and End Results (SEER) cancer registries with Medicare claims data. The linked database covers approximately 25% of the elderly cancer patients living in the United States. The benefit to using linked SEER-Medicare for this analysis is the ability to limit the population to those who died of their cancer and to include additional information about the cancer diagnosis not found on claims.

We chose to study patients with breast, lung, colorectal, prostate and pancreatic cancer because these make up the largest proportion of deaths from cancer.[83] We identified men and women who were diagnosed with these cancers while residing in SEER areas and who subsequently died from their cancer (as reported by the SEER program based on death certificate information) in 2007 or 2008. Patients whose discharge status on the last claim indicated that the patient was still alive and whose Medicare date of death was later than the end date of the last hospice claim, indicating a possible live discharge[104] were excluded from this analysis. Second, patients with unknown race or race other than white, black, Hispanic or Asian were excluded due to small numbers (n=30). The full cohort definition can be found in the appendix.

We first examined the association between location of care and the level of care (LOC) to evaluate the new field on Medicare Hospice claims. The location of care was determined by the healthcare common procedure coding system (HCPCS) code on the hospice claim. LOC describes the intensity of care (routine home care, continuous home care, respite inpatient care to provide relief for caregivers, and respite inpatient care for intensive pain and symptom management) and is found in the revenue center field. For our purposes, HCPCS codes were grouped into home (home or assisted living facility), nursing home (unskilled and skilled nursing facility), hospital (inpatient hospital), hospice (inpatient hospice facility) and other (long-term care hospital, inpatient psychiatric facility and 'not otherwise specified') (Table 1).

The location of death (LOD) is the location of care on the final hospice claim. We used the chi-square test to find meaningful differences in hospice use and LOD by age,

sex, race, urban/rural location, registry, health maintenance organization (HMO) enrollment and type of cancer as well as differences in length of stay by location of death. Length of stay was measured as total time enrolled in hospice, using claim dates. Approximately 10% of hospice enrollees experienced a break in use (defined as more than one day between the end of one claim and the beginning of the next); days during these breaks are not included in the total length of stay. HMO enrollment was measured during the month of hospice entry because we were interested in the effect of HMO enrollment on hospice entry and found that most participants remained enrolled from hospice entry to death; less than 1% of hospice users in our study population were enrolled in an HMO at hospice entry switched to fee-for-service (FFS) prior to death.

We used multivariate logistic regression analyses to find the association of age, sex, race, registry, urban/rural status, HMO enrollment, cancer type, and quartile of median income in the zip code of residence with each dependent variable—hospice use and death at home. An additional logistic regression analysis was performed to examine the association of location of death on the dependent variable optimal length of stay (greater than 7 days and less than 180 days) while controlling for the presence of age, sex, race, registry, urban/rural status, HMO enrollment, cancer type, and quartile of median income in the zip code of residence.

Results

We identified 46,044 patients who died of cancer from 2007 to 2008, and 30,534 (66.3%) of these patients used hospice prior to death. Upon examining all hospice claims (i.e., not simply final claims) for this population, we found that the location of care cannot

be inferred from the level of care code alone. Table 2 describes the association of the LOC and LOD codes among all hospice claims filed for our study population from 2007-2009. The majority (86.2%) of claims that were billed for routine home care (RHC) and 90% of these indicated a home setting as LOC, with 11.7% and 8.2% provided in a nursing home setting. Over 800 claims for RHC indicated an inpatient hospital as the LOC, and over 400 claims for general inpatient care (GIP) indicated a home setting as the LOC.

Among hospice users, location of death varied significantly by the age of the hospice enrollee at death ($p<0.0001$). The proportion dying at home decreased as patient age increased from 73.2% of enrollees aged 65-69 to 66.9% of enrollees over 85. Older hospice enrollees were much more likely to die in a nursing home (19.6% of over 85 year olds vs. 8.1% of enrollees aged 65-69). Sex was also significantly associated with location of death, although the differences were small; men were slightly more likely to die at home and women to die in a nursing home. Hispanic enrollees were much more likely to die at home (76.4%) and blacks the least likely (62.9%) compared to other racial and ethnic groups. Blacks were most likely to die in nursing home, hospice, and inpatient hospice (Table 3).

Hospice enrollees who were enrolled in a Medicare FFS were less likely to die at home than patients enrolled in Medicare HMO (67.3% vs. 76.4%) and more likely to die in a hospital (7.6% vs 3.8%). Hospice enrollees dying of breast and prostate cancer were the least likely to die at home (65.9% and 67.9%, respectively), and those dying of pancreatic cancer were the most likely to die at home (73.6%) (Table 3).

Younger patients, men, blacks and Asians (vs. whites and Hispanics), FFS users, unmarried people, and patients from areas with lower income were less likely to use hospice when controlling for all factors (Table 4). There is significant variation by SEER registry, e.g. for the registry with the most hospice users (Iowa) and the registry with the least (Los Angeles), the odds ratio was 0.31 (95% CI: 0.27-0.35).

In regression analysis predicting death at home (Table 4), geography remained the most important predictor among hospice users with an odds ratio of 10.96 between the registry with the most home deaths (San Francisco) and the registry with least (Iowa). Older patients, patients in urban areas (vs. rural areas (OR: 0.61, 95% CI: 0.48, 0.77)), patients enrolled in FFS Medicare (vs. Medicare HMO (OR: 0.85,95% CI: 0.80, 0.91)), and those who were never married (vs. those who were married (OR: 0.52, 95% CI: 0.47-0.57) were less likely to die at home.

Hospice patients who died in the hospital were more likely than patients who died at home to have a length of stay of less than 7 days (66.9% vs 33.3%, respectively, Figure 1). Location of death was a significant predictor in a multivariate logistic regression model predicting inappropriate length of stay (Table 5). Patients dying in hospitals (OR 4.307, 95% CI: 3.884-4.775), inpatient hospice (OR: 1.56, 95% CI: 1.434-1.698), and nursing homes (95% CI: 1.137, 95% CI: 1.056-1.224) have a higher propensity toward short stay ($\leq$7 days) than patients dying at home after controlling for all other measured factors, while patients dying in nursing homes have a greater odds of long lengths of stay (>180 days) (OR: 1.506, 95% CI: 1.301-1.743).

Discussion

Almost one-third of patients using the MHB died in institutions. Dying at home was more common among groups most likely to use hospice in previous studies: younger patients, Hispanic and Asian patients, patients with pancreatic cancer, and patients enrolled in a Medicare HMO.

Our findings may suggest that hospices have been successful in reaching out to groups for whom death at home was a barrier by providing hospice services in settings other than home. For example, we find that among patients who use hospice, blacks are least likely to die at home. Investigations into this phenomenon have found that black patients often wish not to burden their family caregivers at the end of life or have no access to an informal caregiver[35,105] and therefore could not benefit from hospice provided only in the home. Indeed, we, along with many others,[30,36,58,78,87] find that blacks are the racial group least likely to use hospice. Similarly, patients who were never married or those with limited resources may not have access to family caregivers,[76] and we find that they are least likely to use hospice and least likely to die in the home when hospice is accessed.

We find that patients enrolled in an HMO are also more likely to die at home. This is an interesting finding in that deserves further attention—the MHB is a carve-out, and one would expect that HMO and FFS patients would receive the same care once enrolled in the MHB. Patients enrolled in FFS Medicare have been found previously to enroll in hospice at higher rates than those enrolled in Medicare managed care organizations and have longer lengths of stay, a finding that is replicated here. We also find an association

between LOD and length of stay; perhaps the association between HMO enrollment and longer hospice length of stay earlier may help to explain this finding.

We find that almost a quarter (23.5%) of hospice users were enrolled for less than 3 days. For years, hospice advocates have been hailing the growth in hospice use but have responded with trepidation to the increase in very short stays. The benefits of hospice—the opportunity for patient and family to come to terms with the impending death and access resources to help them emotionally, financially and physically—are diminished with very short stays.[9] Transitioning from one provider to another can create significant organizational, financial, physical and emotional consequences for patients and caregivers.[9,106]

Hospice patients dying in institutional settings have been shown to be more likely to have shorter stays.[99,107] We find that 66.9% of patients who die in the hospital enrolled in hospice less than seven days prior to death, and 50.5% die within three days of enrolling in hospice. These late enrollments probably signal the recognition of imminent death rather than a desire to transition goals of care. It may be prudent to investigate the financial incentives leading to an increase in hospitals electing to discharge a patient to a hospice bed within the same institution. Unlike discharges to other institutions, such as a skilled nursing facility, hospice discharges that result in a shorter than average hospital stay do not result in a reduction in reimbursement for the stay. A hospital collects the full DRG payment (based on the average length of stay) and also collects the general inpatient payment per diem hospice rate.[108]

While we focus on predictors of hospice use, particularly in a home-based setting, we must note that death in the hospital may not be an adverse event. For some, it may provide the welcome opportunity for patients and family members to remain under the care of the hospital staff who have become familiar to them during treatment or at least to have the comfort of professional caregivers.[23] For others, however, it may be a protocol triggered by the recognition of imminent death, leaving patient and family members disoriented by the quick transition. The fact that almost one-half of hospital deaths in hospice occurred in patients enrolled in hospice for less than three days may suggest the latter situation.

On the other hand, nursing home patients are more likely to have very long (>180 days) stays in hospice. Nursing homes are an institutional setting, but they are often where the patient resides. The Medicare benefit has allowed hospice care in nursing homes to be reimbursed as care at home (most often routine home care) since 1986. Nursing homes and hospice both have incentives to enroll residents in hospice care because of overlap of some services provided. Dying nursing home residents may access hospice services in addition to their usual care routines (with the exception of patients using a Medicare reimbursed post-acute care skilled nursing facility visit—hospice is not reimbursed at this time).[109] Nursing homes benefit by the fact that increased clinical personnel are available to the resident in their facility, and hospices benefit by serving multiple patients in one location.[110]

These mutually beneficial arrangements may explain the widespread use of hospice in nursing homes, and this may explain some of our findings concerning the eldest

patients in our study population.[111] We found that among elderly cancer patients, the oldest age group was most likely to use hospice, a finding that contrasts with previous findings.[31,34] We also found that the oldest patients were least likely to have a home death. Concern about use of hospice in nursing homes has increased in the last decade as nursing hospice users within the nursing home population have substantially longer stays than others.[111] It has been proposed that this is a result of inappropriate recruitment practices among hospices, especially by targeting patients with non-cancer diagnoses for whom the terminal decline is unpredictable and may be longer. We find that even among patients admitted to hospice after diagnosis of cancer, the group most likely to have a stay of greater than 180 days is those who die in a nursing home.

The benefits of hospice care extend to any patient who is terminally ill; however, patients with terminal cancer generally experience a dying trajectory most compatible with hospice—a relatively predictable decline.[10] Our analysis provides current information in a representative population of Medicare beneficiaries with cancer. While our study population does not include non-cancer hospice users, the fact that these patterns of use occur even among the prototypical hospice patients suggests that they will be present to an even larger degree among non-cancer hospice users. The large extent of geographic variation even among the SEER registries suggests a need for further evaluation across the rest of the United States. While our analysis focuses on the elderly population, our findings mimic other single and multiple hospice studies with no age restriction.[99,101,107] Patient factors such as lower functional or performance status, lack of caregiver (outside of what can be inferred by marital status) and other factors about the patient's home which

may make it an unsuitable location to die may be important and are unmeasured here; however, this study is a large scale and finds general population trends.

The MHB was designed based on the ideal of hospice as a non-institutional setting. We found that almost a third of patients are not receiving home-based care at the time of death. The decision must be made whether this signifies a need to revisit a) the benefit's design to better match the original goals, b) the goals themselves, or c) the implementation of the benefit. For each site of death, aligning payment incentives with goals of quality care at the end of life will aid in promoting better outcomes. Hospice provided within traditional institutions is necessarily different than hospice provided in the home, yet the payment level does not change whether RHC is provided in a nursing home versus home or GIC is provided in a hospital or a hospice. The addition of HCPCS POS codes to administrative data collection in hospices is a step in the right direction. Using these codes will aid in developing optimal payment policy given how the hospice benefit is used at each site. These codes provide insight into the care that is received and illuminate the fact that "hospice" often does not equal "home."

Table 9. Description of codes used to describe services provided (Revenue Center Codes) and location of services (CPT codes) on Medicare Hospice claims since 2007.

Revenue Center Codes		
0651	Routine Home Care	
0652	Continuous Home Care	
0655	Respite care	
0656	General Inpatient Care	
CPT codes (HCPCS)		**Category**
Q5001	Home	Home
Q5002	Assisted Living Facility	
Q5003	Non-skilled Nursing Home	Nursing Home
Q5004	Skilled Nursing Facility	
Q5005	Inpatient Hospital	Inpatient Hospital
Q5006	Inpatient Hospice facility	Inpatient Hospice
Q5007	Long Term Care Hospital	Other
Q5008	Inpatient Psychiatric Facility	
Q5009	Not Otherwise Specified	
Q5010	Hospice Facility*	N/A

*Code introduced in 2010 (after our period of study) to denote patients receiving care in a hospice residential facility (e.g., receiving routine home care while residing in a hospice facility).

Table 10. Location of services by level of service type for any hospice claim filed for those in the study population, 2007-2008.

	Home	Nursing Home	Hospital	Hospice	Other	Total
Routine Home Care	257,210 86.2%	34,851 11.7%	810 0.3%	1,932 0.6%	3,722 1.2%	298,525 100%
Continuous Home Care	7,205 89.9%	658 8.2%	14 0.2%	34 0.4%	102 1.3%	8,013 100%
Respite care	89 6.4%	524 37.8%	337 24.3%	407 29.3%	30 2.2%	1,387 100%
General Inpatient Care	415 2.7%	1,956 12.7%	5,169 33.5%	7,693 49.9%	181 1.2%	15,414 100%
Total	81.9%	11.7%	2.0%	3.1%	1.2%	323,339 100%

Table 11. Characteristics of Medicare lung, breast, colorectal and pancreatic cancer decedents and location of death among hospice users, 2007-2008

		Total	Hospice users	Location of death				
				Home	Nursing Home	Hospital	Hospice	Other
	Total	**46044**	30,534	21,412	4,049	1,960	2,830	283
	%		66.30	70.10	13.30	6.40	9.30	0.90
Age at death*	**65-69**	**4385**	58.80	73.20	8.10	7.90	10.10	0.60
	70-74	**9246**	63.40	71.90	9.40	6.80	10.80	1.10
	75-79	**11100**	65.90	71.20	11.00	7.00	9.80	1.00
	80-84	**10473**	68.30	69.80	13.80	6.50	9.00	0.90
	85+	**10840**	70.30	66.90	19.60	5.00	7.60	0.90
Sex*	**Female**	**23437**	69.40	69.40	14.30	6.10	9.30	1.00
	Male	**22607**	63.10	71.00	12.10	6.80	9.30	0.80
Race*	**NH-White**	**37099**	67.80	69.80	13.30	6.50	9.50	0.90
	Black	**3978**	58.40	62.90	16.70	9.40	10.20	0.70
	Hispanic	**2827**	66.70	79.10	10.10	3.20	6.40	1.20
	Asian/PI	**2140**	54.70	76.40	11.00	3.90	7.30	1.40
Urban/ Rural‡	**Big Metro**	**27594**	66.50	70.50	13.00	7.20	8.50	0.90
	Metro	**12180**	68.70	70.20	12.60	3.90	12.20	1.10
	Urban	**2405**	61.10	73.00	13.90	6.80	‡	‡
	Less Urban	**3181**	60.40	66.30	17.10	8.80	7.00	0.80
	Rural	**681**	60.50	62.40	19.90	10.90	‡	‡
Registry‡	**San Francisco**	**2372**	62.90	83.70	9.50	1.30	3.00	2.50
	Connecticut	**2570**	63.00	51.60	20.00	14.50	13.20	0.70
	Detroit	**2946**	71.10	56.30	13.20	25.00	‡	‡
	Hawaii	**751**	56.70	68.10	4.20	6.80	17.40	3.50
	Iowa	**2543**	78.30	42.20	26.30	10.10	20.60	0.90
	New Mexico	**1038**	70.50	72.80	8.90	2.20	14.10	2.00
	Seattle	**2642**	65.40	72.50	13.00	4.10	9.10	1.30
	Utah	**788**	79.80	81.10	10.30	3.20	4.90	‡
	Atlanta	**1190**	70.30	55.90	7.20	2.30	32.80	1.90
	San Jose	**1067**	69.40	82.40	15.30	‡	‡	‡
	Los Angeles	**4264**	61.00	78.50	15.30	2.60	3.20	0.40
	Greater California	**10681**	68.90	81.50	10.50	2.10	4.40	1.40
	Kentucky	**3682**	58.70	72.10	7.80	6.70	‡	‡
	Louisiana	**3077**	68.80	71.50	13.60	8.20	‡	‡
	New Jersey	**6433**	62.40	63.20	15.20	7.00	‡	‡

‡Cell not shown due to small numbers, per SEER-Medicare reporting rules
***Chi-square p-value <0.0001**

(Continued on next page)

Table 11 (continued). Characteristics of Medicare lung, breast, colorectal and pancreatic cancer decedents and location of death among hospice users, 2007-2008

		Total	Hospice users	Location of death				
				Home	Nursing Home	Hospital	Hospice	Other
	Total	**46044**	30,534	21,412	4,049	1,960	2,830	283
	%		66.30	70.10	13.30	6.40	9.30	0.90
HMO*	**HMO**	**13251**	72.10	76.40	11.30	3.80	7.60	0.90
	FFS	**32793**	64.00	67.30	14.20	7.60	10.00	0.90
Cancer type*	**Breast**	**4737**	68.70	65.90	18.00	5.40	9.30	1.40
	Colorectal	**8837**	66.50	68.30	15.90	6.00	8.90	0.80
	Lung	**22739**	64.70	71.50	11.50	6.80	9.40	0.80
	Pancreas	**4656**	71.60	73.60	9.00	6.80	9.60	1.10
	Prostate	**5075**	66.10	67.90	16.00	6.30	8.70	1.00
Marital Status*	**Married**	**22319**	66.00	74.20	9.00	6.50	9.40	0.80
	Never Married	**3722**	60.00	60.40	22.00	6.90	9.60	1.10
	Previously	**17928**	68.00	67.60	16.50	6.10	8.90	1.00
	Unknown	**2075**	66.60	65.40	15.70	7.50	10.60	0.90
Median income*	**Q1**	**10895**	61.40	69.20	15.20	6.30	8.60	0.80
	Q2	**10943**	65.50	70.30	13.90	6.50	8.20	1.00
	Q3	**10977**	67.70	70.10	12.80	6.50	9.60	1.00
	Q4	**11015**	70.60	71.10	11.30	6.40	10.40	0.80
	Unknown	**2214**	66.40	68.60	14.10	5.70	10.30	1.30

*Chi-square p-value <0.0001

Table 12. Multivariate logisitic regression analysis results of predicting the association of patient characteristics with use of hospice at death and home death given use of hospice among Medicare beneficiaries who died of lung, colorectal, pancreatic, prostate and breast cancer, 2007-2008.

		Any hospice among all deaths			Death at home among hospice		
		Odds Ratio	95% Confidence Interval	Global p	Odds Ratio	95% Confidence Interval	Global p
Age at death (years)	**65-69**	1		<0.0001	1		0.0002
	70-74	1.17	(1.09, 1.27)		0.9	(0.81, 1.01)	
	75-79	1.29	(1.2, 1.39)		0.89	(0.8, 0.99)	
	80-84	1.43	(1.33, 1.55)		0.86	(0.77, 0.95)	
	85+	1.56	(1.45, 1.69)		0.79	(0.71, 0.88)	
Sex	**Female**	1		<0.0001	1		0.1989
	Male	0.74	(0.7, 0.77)		0.96	(0.9, 1.02)	
Race	**NH-White**	1		<0.0001	1		0.0003
	Black	0.7	(0.65, 0.75)		0.88	(0.8, 0.97)	
	Hispanic	1	(0.91, 1.09)		1.23	(1.09, 1.39)	
	Asian/PI	0.62	(0.56, 0.68)		0.99	(0.85, 1.17)	
Registry	**Iowa**	1		<0.0001	1		<0.0001
	San Francisco	0.34	(0.29, 0.39)		10.96	(9.09, 13.2)	
	Connecticut	0.38	(0.33, 0.43)		1.88	(1.63, 2.17)	
	Detroit	0.56	(0.48, 0.64)		2.89	(2.49, 3.36)	
	Hawaii	0.38	(0.32, 0.47)		2.91	(2.25, 3.75)	
	New Mexico	0.62	(0.52, 0.73)		3.64	(3, 4.41)	
	Seattle	0.41	(0.36, 0.47)		5.04	(4.32, 5.87)	
	Utah	0.91	(0.75, 1.12)		6.6	(5.28, 8.26)	
	Atlanta	0.57	(0.48, 0.67)		2.75	(2.29, 3.3)	
	San Jose	0.46	(0.38, 0.54)		9.26	(7.41, 11.57)	
	Los Angeles	0.31	(0.27, 0.35)		7.64	(6.53, 8.94)	
	Greater California	0.45	(0.4, 0.51)		7.88	(6.95, 8.93)	
	Kentucky	0.4	(0.36, 0.45)		3.98	(3.48, 4.54)	
	Louisiana	0.6	(0.53, 0.68)		4.04	(3.53, 4.63)	
	New Jersey	0.36	(0.32, 0.41)		3.67	(3.21, 4.21)	

Table 12 (continued). Multivariate logisitic regression analysis results of predicting the association of patient characteristics with use of hospice at death and home death given use of hospice among Medicare beneficiaries who died of lung, colorectal, pancreatic, prostate and breast cancer, 2007-2008.

		Any hospice among all deaths			Death at home among hospice		
		Odds Ratio	95% Confidence Interval	Global p	Odds Ratio	95% Confidence Interval	Global p
Urban/ rural	**Big Metro**	1.5	(1.26, 1.79)	<0.0001	0.61	(0.48, 0.77)	<0.0001
	Metro	1.43	(1.2, 1.7)		0.83	(0.66, 1.04)	
	Urban	1.07	(0.89, 1.29)		1.23	(0.96, 1.58)	
	Less Urban	0.96	(0.8, 1.14)		1.05	(0.83, 1.33)	
	Rural	1			1		
HMO	**HMO**	1		<0.0001	1		<0.0001
	FFS	0.696	(0.67, 0.727)		0.852	(0.8, 0.91)	
Cancer type	**Prostate**	1		<0.0001	1		<0.0001
	Breast	0.87	(0.79, 0.96)		0.94	(0.83, 1.06)	
	Colorectal	0.93	(0.86, 1.01)		1.03	(0.93, 1.14)	
	Lung	0.92	(0.86, 0.99)		1.17	(1.07, 1.29)	
	Pancreas	1.24	(1.13, 1.36)		1.26	(1.12, 1.42)	
Marital Status	**Married**	1		<0.0001	1		<0.0001
	Never Married	0.83	(0.78, 0.9)		0.52	(0.47, 0.57)	
	Previously Married	0.98	(0.94, 1.03)		0.73	(0.69, 0.78)	
	Unknown	0.98	(0.89, 1.08)		0.72	(0.64, 0.82)	

Figure 5. Length of stay in hospice by location of death among Medicare hospice users who died of lung, prostate, breast, colorectal and pancreatic cancer, 2007-2008.

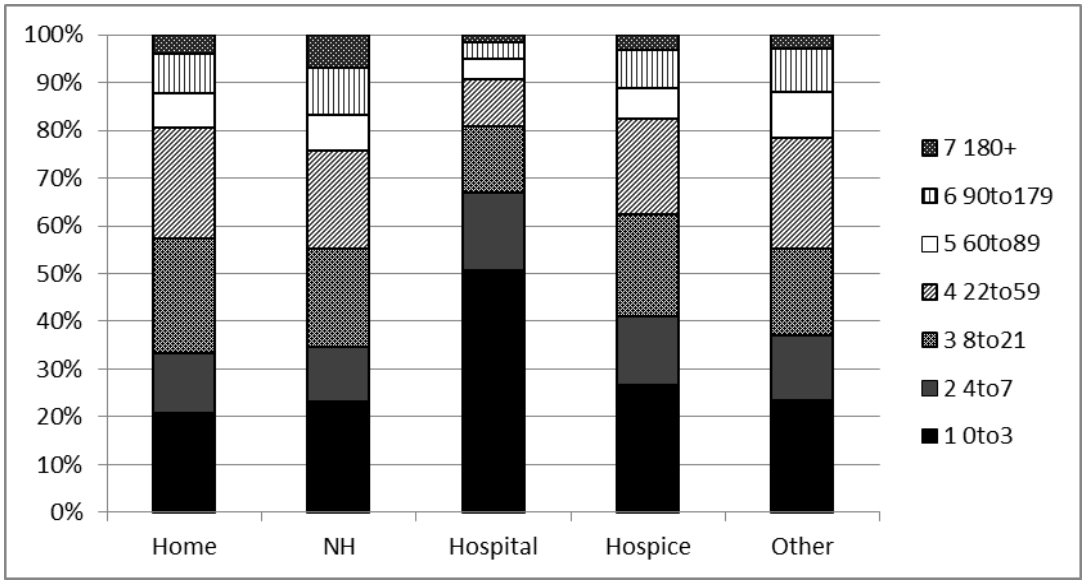


Table 13. Logistic regression analysis* predicting inappropriate length of stay (<7 and >180 days)

		Length of stay ≤7 days			Length of stay >180 days users		
		Odds Ratio	95% Confidence Interval	Global p	Odds Ratio	95% Confidence Interval	Global p
Location of Death	**Home**	1		<0.0001	1		<0.0001
	Nursing Home	1.137	(1.056, 1.224)		1.506	(1.301, 1.743)	
	Hospital	4.307	(3.884, 4.775)		0.408	(0.281, 0.955)	
	Hospice	1.56	(1.434, 1.698)		0.761	(0.646, 1.315)	
	Other	1.205	(0.943, 1.54)		0.646	(0.38, 0.802)	

*Multivariate model including registry, age, sex, race, HMO vs. FFS, urban/rural status, marital status and zip code median income.

Conclusion

The Medicare Hospice Benefit (MHB) was introduced to provide an alternative to the increasingly aggressive and institutionalized care at the end of life. The scope of the MHB was tightly circumscribed to provide non-institutional care for up to six months prior to death for patients who desired care that acknowledged the fact that they were dying.[112] The three papers above challenge common assumptions about how the MHB is used. The first analysis describes the disparity in hospice use between blacks and non-Hispanic whites over time. We find that although the disparity remains throughout our observation period, our ability to explain the disparity has decreased over time. The second analysis finds that lung cancer patients who use no treatment or one treatment use hospice at the same rate as patients who use very aggressive care (3 or more treatments), while patients who use less aggressive care use significantly less. The final analysis describes the place of death among MHB users with cancer. Almost one-third of patients died in institutional settings. Those who died in institutional settings had less optimal length of hospice stay than those who died at home.

With greatly increased use of hospice in the last two decades, the profile of hospice and hospice users has also changed. Hospice use increased over time, but the proportion of hospice users with optimal lengths of stay decreased. [34,113,114] The increase in use, however, does not mean that barriers to accessing hospice no longer exist. When we unpack the well-established fact that blacks use hospice less often than whites, we find that this disparity has remained unchanged over time. In fact, in recent years

differences in demographic and clinical characteristics between these groups explain less of the difference in use between blacks and whites.

The MHB requires cessation of curative treatment or treatment aimed at life extension because users cannot access Medicare payment for these treatments while using the MHB. While this may seem to imply that patients who use hospice prior to death forgo treatment in order to do so, we instead find that patients that use aggressive treatment are just as likely to use hospice as patients who use no treatment. Investigating treatment patterns from diagnosis to death allows us to determine the relationship between cancer care and hospice care.

Finally, the MHB is designed for most of the care to be provided in non-institutional homelike settings, so for many, "hospice" means "home." We find, however, that a third of the patients who died from the some of the most common cancers did not die at home. Payments from the MHB do not take into account location of care despite the fact that patients who die in hospitals and nursing homes have access to formal caregivers and services. The recent addition of a field on the billing statement to indicate location of care is an important step in understanding how and where the benefit is being used.

As the MHB faces challenges associated with regulatory barriers to enrollment and increased use by non-traditional users, the payment structure is under review. Empirical studies will be necessary to inform possible solutions. The findings from the three analyses in this thesis may help to guide this discussion.

Policy implications

In each of these analyses, we find that many patients are using the benefit in suboptimal ways that are challenging given the benefit's payment design. Patients with very long stays in hospice (greater than 180 days) are expensive for the Medicare program because the hospice collects payment for each day of enrollment. While some patients defy prognostic expectations, there is concern that there is a financial incentive for the hospice to enroll these patients too early. Patients who survive for longer than 180 days may have received a benefit from treatment aimed at their terminal condition or from rehabilitative care that is not the specialty of hospice providers.[45] Patients with very short lengths of stays (less than 7 days) present a challenge to hospice because newly admitted and actively dying patients consume large amounts of resources and there are no periods with relatively little resource use during which to recoup the cost. There may be financial incentives for hospitals or other care providers to enroll patients who are imminently dying in hospice. It is also possible that there is a cultural and/or administrative shift among medical providers that hospice is where you "send" patients who are dying, and the recognition of and acceptance of death comes late in many cases. One week is not enough time for patients to receive adequate physical, psychosocial and spiritual care provided by hospice.[45] Patients who receive more aggressive treatment experience shorter lengths of stay than patients who receive no cancer-directed treatment. Patients dying in institutional locations are more likely than those who die at home to have a length of hospice enrollment that is very short or very long.

The MHB was designed with a particular patient in mind—a patient who receives a diagnosis of an illness that is likely terminal and wants to opt out of traditional medicine and dying within an institution and receive optimal care along the way. For this patient, the benefit is well designed. The large increases in hospice use may provide the sense that this benefit is in high demand and accessed by those who desire it. The increase in the number of hospices has been said to demonstrate the sufficiency of the payment rates.

The day a person will die is unknowable, making the optimal time to enroll in hospice difficult to ascertain.[9] Physicians may find it difficult to determine and/or communicate an accurate prognosis, and patients may choose not to hear it. This may result in delaying hospice entry until death is imminent. Increases in very short stays over time suggest that this may be a systemic problem.

These very short visits place a strain on hospices due to the capitated payment system. A person newly admitted to hospice and a person near death generally require more hospice resources so when a person is admitted to hospice for less than three days, there is no chance to recoup those increased costs with payments for days that require fewer resources.

The payment could be reformed to better accommodate patients with very short or very long stays, a proposal that has been studied and recommended by the Medicare Payment Advisory Commission.[115] They have described the u-shaped costs of caring for a hospice patient, with higher costs upon admission as the providers learn about the patient and family and begin to treat their symptoms and higher costs in the last days of

care, when the patient is actively dying. Under the proposed payment reform, payments would be higher on days closer to admission and death. Increasing payments for these stays will likely increase the proportion of very short stays as there would be greater incentive. Given that hospice care received under this scenario looks different than hospice care for longer lengths of stay, another option may be to consider these to be different services altogether—"acute" vs. "chronic" care of the dying. Actively dying patients could be offered something that is not called hospice; perhaps in the inpatient setting, an end-of-life stay modifier might enable hospitals to provide inpatient specialized services to dying patients.[116]

The findings in our final analysis highlight some reasons to make this change. Almost two thirds of patients who die in the hospital inpatient setting are enrolled in hospice for one week or less, and almost half who die in the hospital are enrolled for three days or fewer. Concerns have arisen about hospitals effectively receiving dual payment (receiving the full diagnosis related grouping (DRG payment) plus a hospice payment) for this enrollment.[108] Hospitals may have financial incentives to discharge patients to hospice, especially if the hospice is operated under the auspices of the same parent organization and perhaps in the same building. In these cases, the hospital to hospice transition is more bookkeeping than care. While there would be a need for tight oversight to ensure that hospitals were billing appropriately, changing the payment instead to reimburse for an end of life hospital stay would provide flexibility for the hospital to provide end of life care or contract with another organization to provide it.

Open access hospice is another policy proposal that is frequently discussed.[97] In this model, hospice care remains the same, providing symptom management and psychosocial care, but providers can also be reimbursed for treatments aimed at managing the terminal condition. For example, a patient may receive chemotherapy to shrink a tumor while enrolled in hospice. There are many possible benefits: this would remove the barrier to hospice to those who wish to receive more curative or life extending treatment, or are simply unwilling to admit that there are no other curative options. This could also reduce the number of short stays in hospice because people will not have to wait to "complete" treatments in order to enroll, and this would help remove the barrier for expensive treatments such as chemotherapy or radiotherapy which are primarily aimed at reducing suffering but may also extend life. Currently, while hospices may provide such treatment if it is deemed palliative, capitated payments prevent all but the largest hospices from doing so.[117] If the goal is for more people to access the expertise of end of life specialists, this may help to further that goal. The goal of cost savings as a result of hospice enrollment is less clear cut. We found that many patients enrolled in hospice after receiving treatments, so there may be no difference in costs of treatments for the terminal condition, and there is the potential for cost savings by reducing the number of health care encounters for crises of symptom management or psychological distress. However, the cost of hospice would increase if patients enrolled earlier, and the current issue faced by those who receive hospice care in hospitals and nursing homes, duplication of services, would be increased.

Finally, whether the model is open access hospice or simply patients receiving care from a non-hospice palliative care program, the goals of care become murkier. While patients who are not forced to choose between curative and palliative may more easily come to a realization that they will die soon and plan accordingly, it is likely that it would, in fact, be more difficult. One of the most profound intangible benefits is the chance for patients and their families to take the actions they want to be able to take before they die.[22] If the goal is to increase this benefit for patients and their families, it must start with the acknowledgement of medical care limitations and clear communication of those limitations by all providers. Simply discussing the hospice option may increase awareness.[85] One single institution study found that of over half of patients who died in their hospital were hospice eligible according to guidelines published by the National Hospice and Palliative Care Organization (NHPCO), yet only 10% of these patients were offered hospice prior to the terminal hospitalization.[26] Particularly for blacks, increased knowledge about the hospice option may increase use.[35,118]

While the disparity in use for black patients remains unchanged, our ability to explain the difference using other demographic differences has decreased. The literature suggests that blacks are more likely to prefer dying in a hospital versus at home, and to prefer aggressive treatment to hospice care.[32,70,86,119] Despite these preferences, in our analysis, black patients were less likely to receive very aggressive treatment than other racial groups. We also found that patients using only one or two treatments were less likely to use hospice than those using no treatments or 3 or more treatments. Is it any

wonder that a patient who hasn't been offered the full range of treatment is less likely to give up the opportunity to receive more? Perhaps, counterintuitively, interventions to improve access to hospice for minorities are better directed at interventions to improve access to curative treatments at diagnosis, particularly for African Americans.

Another strategy to improve access for blacks is to continue expanding the choices for hospice care. A subgroup investigation in our final analysis reveals that although black hospice users are more likely to die the in the hospital than any other group, they are the least likely among users dying in the hospital to experience a very short length of stay. For this group, enrolling in hospice within a hospital seems to be more intentional than other groups and probably does signal a preference to receive end of life care in a hospital or lack of caregiver in the home,[35,105] rather than a transition in billing from hospital to hospice when death appears to be imminent. Improving end of life care within hospitals may help this population as well with the additional caveat that quality of care must be monitored.

The calls for improved communication between physicians and patients at the end of life, improved non-hospice medical care, and improved inpatient end of life care[8,120] are not new or controversial and they are also difficult to implement.[121] Hospice payment reform is more easily implemented but the goal must be clear and the incentives need to be carefully thought out. Our data have shown that hospice payment policy has achieved the goal of increased the number of hospice users and the number of hospices, but it has not reached all populations and does not serve all users well.

Facing mortality or the death of a loved one is difficult; the health care system should not add to the difficulty by delivering unwanted care or inadequate symptom management and support. The MHB has served millions of users and is associated with patient satisfaction and improved outcomes for bereaved caregivers. Our analyses have peered into the MHB black box to illuminate the continued racial disparity in hospice use, the relationship between curative treatment and hospice use, and where hospice users die. We examined how cancer patients, for whom the benefit was originally designed, use the MHB. To know that even these patients are using the benefit in ways that differ from what was originally intended will inform the discussion of the future of the Medicare to insure excellent end of life care is delivered to all patients near death.

References

1. American Society of Clinical Oncology (ASCO). Cancer care during the last phase of life. *J. Clin. Oncol.* 1998;16(5):1986–96.

2. Wallston K a, Burger C, Smith R a, Baugher RJ. Comparing the quality of death for hospice and non-hospice cancer patients. *Med. Care*. 1988;26(2):177–82.

3. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291(1):88–93.

4. Earle CC, Souza JM, Neville BA, Weeks JC, Block SD, Ayanian JZ. Identifying potential quality of care indicators for end-of-life cancer care from administrative data Major Themes Feasibility assessment Methods : Performance Empirical determination of achievable benchmarks Results : Achievable Benchmarks Results : Vari. 2003:1–4.

5. (MedPAC) MPAC. *Report to the Congress: Medicare Payment Policy. Chapter 12. Hospice services*. Washington, D.C.; 2013.

6. Christakis N a, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N. Engl. J. Med.* 1996;335(3):172–8.

7. Iwashyna T, Christakis N. Attitude and self-reported practice regarding hospice referral in a national sample of internists. *J. Palliat. Med.* 1998;1(3):241–248.

8. Lau F, Downing GM, Lesperance M, Shaw J, Kuziemsky C. Use of Palliative Performance Scale in end-of-life prognostication. *J. Palliat. Med.* 2006;9(5):1066–75.

9. Christakis NA. Timing of referral of terminally ill patients to an outpatient hospice. *J. Gen. Intern. Med.* 1994;9(6):314–20.

10. Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *J. Palliat. Med.* 2001;4(4):457–64.

11. Abel EK. The hospice movement: institutionalizing innovation. *Int. J. Health Serv.* 1986;16(1):71–85.

12. Dietvorst MHP, Eskens FALM. Current and Novel Treatment Options for Metastatic Colorectal Cancer: Emphasis on Aflibercept. *Biol. Ther.* 2013;3(1):25–33.

13. Antonarakis ES, Eisenberger MA. Expanding treatment options for metastatic prostate cancer. *N. Engl. J. Med.* 2011;364(21):2055–8.

14. De Laurentiis M, Cianniello D, Caputo R, et al. Treatment of triple negative breast cancer (TNBC): current options and future perspectives. *Cancer Treat. Rev.* 2010;36 Suppl 3:S80–6.

15. Li J, Wientjes MG, Au JL-S. Pancreatic cancer: pathobiology, treatment options, and drug delivery. *AAPS J.* 2010;12(2):223–32.

16. (MedPAC) MPAC. *Payment Basics. Hospice services payment system*. Washington, D.C.; 2012.

17. *Tax Equity and Fiscal Responsibility Act of 1982*.; 1982.

18. Centers for Medicare and Medicaid Services (CMS). Medicare Benefit Policy Manual Chapter 9 - Coverage of Hospice Services Under Hospital Insurance. 2011.

19. Caffrey C, Sengupta M, Moss A, Harris-Kojetin L, Valverde R. Home health care and discharged hospice care patients: United States, 2000 and 2007. *Natl. Health Stat. Report.* 2011;(38):1–27.

20. Christakis N a, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc. Sci. Med.* 2003;57(3):465–75.

21. Steinhauser KE, Clipp EC, McNeilly M, Christakis N a, McIntyre LM, Tulsky J a. In search of a good death: observations of patients, families, and providers. *Ann. Intern. Med.* 2000;132(10):825–32.

22. Hoyer T. A history of the Medicare hospice benefit. Harrold JK, Lynne J, eds. *Hosp. J.* 1998;13(1-2):61–9.

23. Tang ST. When death is imminent: where terminally ill patients with cancer prefer to die and why. *Cancer Nurs.* 2003;26(3):245–251.

24. Emanuel LL, Alpert HR, Baldwin DC, Emanuel EJ. What terminally ill patients care about: toward a validated construct of patients' perspectives. *J. Palliat. Med.* 2000;3(4):419–31.

25. Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J. Am. Geriatr. Soc.* 1998;46(10):1242–50.

26. Freund K, Weckmann MT, Casarett DJ, Swanson K, Brooks MK, Broderick A. Hospice eligibility in patients who died in a tertiary care center. *J. Hosp. Med.* 2012;7(3):218–23.

27. Earle CC, Neville B a, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *J. Clin. Oncol.* 2004;22(2):315–21.

28. Huskamp H a., Buntin MB, Wang V, Newhouse JP. Providing Care At The End Of Life: Do Medicare Rules Impede Good Care? *Health Aff.* 2001;20(3):204–211.

29. Buntin MB, Huskamp H. What is known about the economics of end-of-life care for medicare beneficiaries? *Gerontologist*. 2002;42 Spec No(Iii):40–8.

30. Colon M, Lyke J. Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *Am. J. Hosp. Palliat. Med.* 2003;20(3):182–190.

31. Virnig BA, Mcbean AM, Kind S, Dholakia R. Hospice Use Before Death Across Cancer Diagnoses. *Med. Care*. 2002;40(1):73–78.

32. Krakauer EL, Crenner C, Fox K. Barriers to optimum end-of-life care for minority patients. *J. Am. Geriatr. Soc.* 2002;50(1):182–90.

33. Neubauer BJ, Hamilton CL. Racial differences in attitudes toward hospice care. *Hosp. J.* 1990;6(1):37–48.

34. Lackan NA, Ostir G V, Freeman JL, Mahnken JD, Goodwin JS. Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. *Med. Care*. 2004;42(2):116–22.

35. Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J. Palliat. Med.* 2004;7(2):247–56.

36. Fishman J, O'Dwyer P, Lu HL, Henderson H, Asch DA, Casarett DJ. Race, treatment preferences, and hospice enrollment: Eligibility criteria may exclude patients with the greatest needs for care. *Cancer*. 2009;115(3):689–697.

37. Connor SR, Elwert F, Spence C, Christakis N a. Geographic variation in hospice use in the United States in 2002. *J. Pain Symptom Manage.* 2007;34(3):277–85.

38. Virnig BA, Kind S, McBean M, Fisher E. Geographic variation in hospice use prior to death. *J. Am. Geriatr. Soc.* 2000;48(9):1117–25.

39. Barnato AE, Herndon MB, Anthony DL, et al. Are regional variations in end-of-life care intensity explained by patient preferences?: A Study of the US Medicare Population. *Med. Care*. 2007;45(5):386–93.

40. McCarthy EP, Burns RB, Ngo-Metzger Q, Davis RB, Phillips RS. Hospice use among Medicare managed care and fee-for-service patients dying with cancer. *JAMA*. 2003;289(17):2238–45.

41. Virnig BA, Fisher ES, Mcbean AM, Kind S. Hospice use in Medicare managed care and fee-for-service systems. *Am. J. Manag. Care*. 2001;7(8):777–86.

42. Virnig BA, Persily NA, Morgan RO, DeVito CA. Do Medicare HMOs and Medicare FFS differ in their use of the Medicare hospice benefit? *Hosp. J.* 1999;14(1):1–12.

43. Virnig BA, Morgan RO, Persily NA, DeVito CA. Racial and income differences in use of the hospice benefit between the medicare managed care and medicare fee-for-service. *J. Palliat. Med.* 1999;2(1):23–31.

44. Somova M, Somov P, Lawrence J, Frantz T. Factors associated with length of stay in a mid-sized, urban hospice. *Am. J. Hosp. Palliat. Med.* 2000;17(2):99–105.

45. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N. Engl. J. Med.* 1996;335(3):172–8.

46. Virnig BA, Baxter NN, Habermann EB, Feldman RD, Bradley CJ. A matter of race: early-versus late-stage cancer diagnosis. *Health Aff. (Millwood).* 2009;28(1):160–8.

47. Singh GK, Miller BA, Hankey BF, Edwards BK. *Area Socioeconomic Variations in U . S . Cancer Incidence , Mortality , Stage , Treatment , and Survival , 1975 – 1999. NCI Cancer Surveillance Monograph Series, Number 4. NIH Publication No. 03-5417.* Bethesda, MD; 2003.

48. Merrill RM, Merrill A V, Mayer LS. Factors associated with no surgery or radiation therapy for invasive cervical cancer in Black and White women. *Ethn. Dis.* 2000;10(2):248–56.

49. Sundararajan V, Hershman D, Grann VR, Jacobson JS, Neugut AI. Variations in the use of chemotherapy for elderly patients with advanced ovarian cancer: a population-based study. *J. Clin. Oncol.* 2002;20(1):173–8.

50. Bach PB, Cramer LD, Warren JL, Begg CB. Racial differences in the treatment of early-stage lung cancer. *N. Engl. J. Med.* 1999;341(16):1198–205.

51. Levinsky NG, Yu W, Ash a, et al. Influence of age on Medicare expenditures and medical care in the last year of life. *JAMA.* 2001;286(11):1349–55.

52. Gagnon B, Mayo NE, Hanley J, MacDonald N. Pattern of care at the end of life: does age make a difference in what happens to women with breast cancer? *J. Clin. Oncol.* 2004;22(17):3458–65.

53. Ganz PA. Age and gender as factors in cancer therapy. *Clin. Geriatr. Med.* 1993;9(1):145–55.

54. Bird CE, Shugarman LR, Lynn J. Age and gender differences in health care utilization and spending for medicare beneficiaries in their last years of life. *J. Palliat. Med.* 2002;5(5):705–12.

55. Iwashyna TJ, Zhang JX, Christakis NA. Disease-Specific Patterns of Hospice and Related. 2002;5(4).

56. Riley GF, Potosky AL, Klabunde CN, Warren JL, Ballard-Barbash R. Stage at Diagnosis and Treatment Patterns Among Older Women With Breast Cancer. *JAMA.* 1999;281(8):720.

57. Warren JL, Yabroff KR, Meekins A, Topor M, Lamont EB, Brown ML. Evaluation of Trends in the Cost of Initial Cancer Treatment. *Cancer Control*. 2008;100(12).

58. Han B, Remsburg RE, Iwashyna TJ. Differences in hospice use between black and white patients during the period 1992 through 2000. *Med. Care*. 2006;44(8):731–7.

59. Sengupta M, Park-Lee E, Valverde R, Caffrey C, Jones A. Trends in Length of Hospice Care From 1996 to 2007 and the Factors Associated With Length of Hospice Care in 2007: Findings From the National Home and Hospice Care Surveys. *Am. J. Hosp. Palliat. Care*. 2013.

60. Smith AK, Earle CC, McCarthy EP. Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J. Am. Geriatr. Soc.* 2009;57(1):153–8.

61. Stein WM, Miech RP. Cancer pain in the elderly hospice patient. *J. Pain Symptom Manage.* 1993;8(7):474–82.

62. Emanuel EJ, Emanuel LL. The economics of dying. The illusion of cost savings at the end of life. *N. Engl. J. Med.* 1994;330(8):540–4.

63. Emanuel EJ. Cost savings at the end of life. What do the data show? *JAMA.* 1996;275(24):1907–14.

64. Miller SC, Intrator O, Gozalo P, Roy J, Barber J, Mor V. Government Expenditures at the End of Life for Short-and Long-Stay Nursing Home Residents: Differences by Hospice Enrollment Status. *J. Am. Geriatr. Soc.* 2004;52(8):1284–1292.

65. Kidder D. The effects of hospice coverage on Medicare expenditures. *Health Serv. Res.* 1992;27(2):195–217.

66. Lynn J, Arkes HR, Stevens M, et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment. *J. Am. Geriatr. Soc.* 2000;48(5 Suppl):S214–21.

67. Drought TS, Koenig B a. "Choice" in end-of-life decision making: researching fact or fiction? *Gerontologist*. 2002;42 Spec No(Iii):114–28.

68. Kaufman SR. *And a Time to Die: How American Hospitals Shape the End of Life*. New York, NY: Scribner; 2005.

69. Murray MA, Fiset V, Young S, Kryworuchko J. Where the dying live: a systematic review of determinants of place of end-of-life cancer care. *Oncol. Nurs. Forum*. 2009;36(1):69–77.

70. Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J. Clin. Oncol.* 2008;26(25):4131–7.

71. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of Death : Correlations With Quality of Life of Patients With Cancer and Predictors of Bereaved Caregivers ' Mental Health. *J. Clin. Oncol.* 2013;28(29):4457–4464.

72. (NCI) NCI. SEER Registry Groupings for Analyses. Available at: http://seer.cancer.gov/registries/terms.html. Accessed November 17, 2013.

73. Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *J. Palliat. Med.* 2001;4(4):457–64.

74. Warren JL, Klabunde CN, Schrag D, Bach PB, Riley GF. Overview of the SEER-Medicare Data to the United States. *Med. Care*. 2002;40(8 Supplement IV):IV3–IV8.

75. (MedPAC) MedPAC. *Report to the Congress. Hospice services*. Washington, D.C.; 2012.

76. Lackan N, Ostir G, Kuo Y. The association of marital status and hospice use in the USA. *Palliat. Med.* 2005:160–163.

77. Virnig BA, Moscovice IS, Durham SB, Casey MM. Do rural elders have limited access to Medicare hospice services? *J. Am. Geriatr. Soc.* 2004;52(5):731–5.

78. Connor SR, Elwert F, Spence C, Christakis N a. Racial disparity in hospice use in the United States in 2002. *Palliat. Med.* 2008;22(3):205–13.

79. Connor SR. U.S. hospice benefits. *J. Pain Symptom Manage.* 2009;38(1):105–9.

80. Teno J, Gozalo P, Bynum J, et al. Change in End-of-Life Care for Medicare Beneficiaries. *JAMA.* 2013;309(5):470–477.

81. Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. *J. Natl. Cancer Inst.* 2006;98(15):1053–9.

82. Hardy D, Chan W, Liu C-C, et al. Racial disparities in length of stay in hospice care by tumor stage in a large elderly cohort with non-small cell lung cancer. *Palliat. Med.* 2012;26(1):61–71.

83. Siegel R, Naishadham D, Jemal A. Cancer Statistics , 2012. *Cancer Journal, The*. 2012.

84. Johnson RB, Onwuegbuzie a. J, Turner L a. Toward a Definition of Mixed Methods Research. *J. Mix. Methods Res.* 2007;1(2):112–133.

85. Huskamp HA, Keating NL, Malin JL, et al. Discussions with physicians about hospice among patients with metastatic lung cancer. *Arch. Intern. Med.* 2009;169(10):954–62.

86. Johnson KS, Kuchibhatla M, Tulsky JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J. Am. Geriatr. Soc.* 2008;56(10):1953–8.

87. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. *J. Am. Geriatr. Soc.* 2003;51(7):970–8.

88. Ward E, Jemal A, Cokkinides V, et al. Cancer disparities by race/ethnicity and socioeconomic status. *CA. Cancer J. Clin.* 2010;54(2):78–93.

89. Connor S. Development of Hospice and Palliative Care in the United States. *OMEGA J. Death Dying*. 2007;56(1):89–99.

90. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. *J. Pain Symptom Manage.* 2004;28(3):200–10.

91. Taylor DH, Ostermann J, Van Houtven CH, Tulsky J a, Steinhauser K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? *Soc. Sci. Med.* 2007;65(7):1466–78.

92. Earle CC, Landrum MB, Souza JM, Neville B a, Weeks JC, Ayanian JZ. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J. Clin. Oncol.* 2008;26(23):3860–6.

93. Miller SC, Lima JC, Mitchell SL. Influence of hospice on nursing home residents with advanced dementia who received Medicare-skilled nursing facility care near the end of life. *J. Am. Geriatr. Soc.* 2012;60(11):2035–41.

94. Davidoff AJ, Tang M, Seal B, Edelman MJ. Chemotherapy and survival benefit in elderly patients with advanced non-small-cell lung cancer. *J. Clin. Oncol.* 2010;28(13):2191–7.

95. Klabunde CN, Potosky AL, Legler JM, Warren JL. Development of a comorbidity index using physician claims data. *J. Clin. Epidemiol.* 2000;53(12):1258–67.

96. Temel JS, McCannon J, Greer J a, et al. Aggressiveness of care in a prospective cohort of patients with advanced NSCLC. *Cancer*. 2008;113(4):826–33.

97. Wright AA, Katz IT. Letting Go of the Rope — Aggressive Treatment , Hospice Care, and Open Access. *N. Engl. J. Med.* 2007;357(4):324–327.

98. Greer JA, Pirl WF, Jackson VA, et al. Effect of Early Palliative Care on Chemotherapy Use and End-of-Life Care in Patients With Metastatic Non-Small-Cell Lung Cancer. *J. Clin. Oncol.* 2011:1–7.

99. Miller SC, Kinzbrunner B, Pettit P, Williams JR. How does the timing of hospice referral influence hospice care in the last days of life? *J. Am. Geriatr. Soc.* 2003;51(6):798–806.

100. Amenta MO. Hospice in the United States. Multiple models and varied programs. *Nurs. Clin. North Am.* 1985;20(2):269–79.

101. Jeurkar N, Farrington S, Craig TR, et al. Which hospice patients with cancer are able to die in the setting of their choice? Results of a retrospective cohort study. *J. Clin. Oncol.* 2012;30(22):2783–7.

102. Johnson KS, Kuchibhatala M, Sloane RJ, Tanis D, Galanos AN, Tulsky JA. Ethnic differences in the place of death of elderly Hospice Enrollees. *J. Am. Geriatr. Soc.* 2005;53:2209–2215.

103. Centers for Medicare and Medicaid Services (CMS). Chapter 11. Processing Hospice Claims. In: *Medicare Claims Processing Manual*.; 2010.

104. Carlson MDA, Herrin J, Du Q, et al. Hospice Characteristics and the Disenrollment of Patients with Cancer. *Health Serv. Res.* 2009:2004–2021.

105. Washington KT, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: a systematic review. *Health Soc. Work.* 2008;33(4):267–74.

106. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? *Gerontologist*. 2002;42 Spec No(Iii):54–67.

107. Stevenson DG, Huskamp H a, Grabowski DC, Keating NL. Differences in hospice care between home and institutional settings. *J. Palliat. Med.* 2007;10(5):1040–7.

108. General O of the I. *Medicare could save millions by implementing a hospital transfer payment policy for early discharges to hospice care*.; 2013.

109. Aragon K, Covinsky K, Miao Y, Boscardin WJ, Flint L, Smith AK. Use of the Medicare posthospitalization skilled nursing benefit in the last 6 months of life. *Arch. Intern. Med.* 2012;172(20):1573–9.

110. Petrisek AC, Mor V. Hospice in nursing homes: a facility-level analysis of the distribution of hospice beneficiaries. *Gerontologist*. 1999;39(3):279–90.

111. Miller SC, Lima J, Gozalo PL, Mor V. The growth of hospice care in U.S. nursing homes. *J. Am. Geriatr. Soc.* 2010;58(8):1481–8.

112. United States Senate Committee on Finance. *Background materials on the Medicare Hospice Benefit Including description of proposed implementing regulations*. Washington, D.C.; 1983.

113. Han B, Remsburg RE, McAuley WJ, Keay TJ, Travis SS. National trends in adult hospice use: 1991-1992 to 1999-2000. *Health Aff. (Millwood).* 2006;25(3):792–9.

114. Thompson JW, Carlson MDA, Bradley EH. US hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status. *Health Aff. (Millwood).* 2012;31(6):1286–93.

115. (MedPAC) MedPAC. *Hospice--Online Appendix 11-A*. Washington, D.C.; 2011.

116. Raphael C, Ahrens J, Fowler N. Financing end-of-life care in the USA. *J. R. Soc. Med.* 2001;94(9):458–61; discussion 466–7.

117. Jarosek SL, Virnig B a, Feldman R. Palliative radiotherapy in Medicare-certified freestanding hospices. *J. Pain Symptom Manage.* 2009;37(5):780–7.

118. Taxis JC. Attitudes, values and questions of African Americans regarding participation in hospice programs. *J. Hosp. Palliat. Nurs.* 2006;8(2):77–85.

119. Johnson K, Kuchibhatla M, Tulsky JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J. Am.* …. 2008;56(May 2008):1953–1958.

120. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch. Intern. Med.* 2008;168(16):1783–90.

121. Cassel CK, Ludden JM, Moon GM. Perceptions of barriers to high-quality palliative care in hospitals. *Heal. Aff.* 2000;19(5):166–172.

Appendix A: Additional data and analyses for Paper 1

Figure A1. Cohort Ascertainment

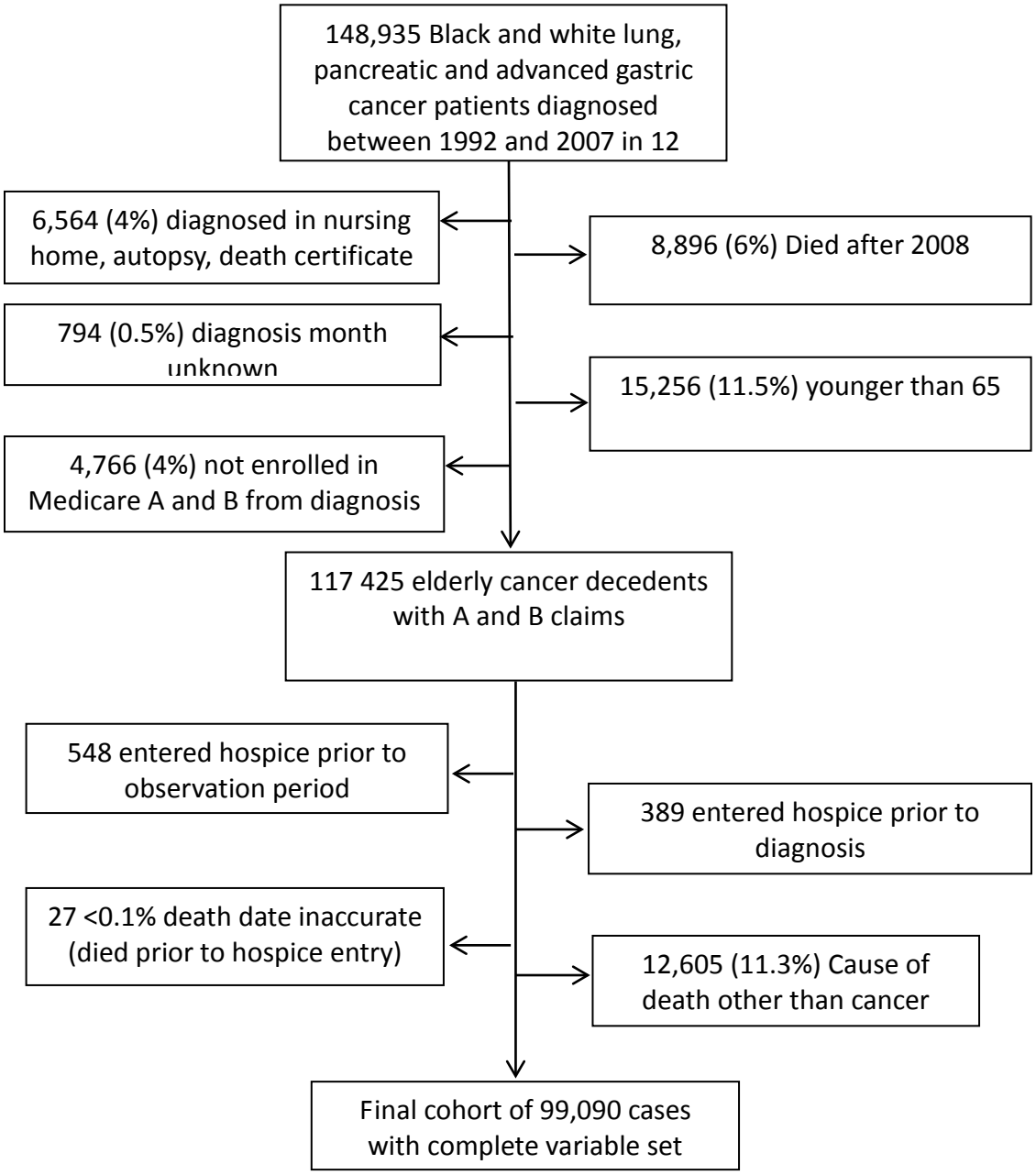


Table A1. Coefficients from "whites only" regression predicting hospice use prior to death for the first and last time periods, used to calculate Peters-Belson estimate.

	1992-1995			2004-2008		
	Coefficient	Se	p	Coefficient	Se	p
Intercept	-0.2337	0.1341	0.0813	0.7467	0.1998	0.0002
Income Q2 vs Q1	0.2269	0.0759	0.0028	0.0178	0.1267	0.888
Income Q2 vs Q1	0.3951	0.0863	<.0001	0.1814	0.1381	0.1889
Income Q2 vs Q1	0.3336	0.1006	0.0009	0.3902	0.1535	0.011
Education Q2 vs Q1	-0.2655	0.0746	0.0004	0.0562	0.1202	0.6401
Education Q2 vs Q1	-0.1908	0.0833	0.022	-0.0876	0.1293	0.4979
Education Q2 vs Q1	-0.1619	0.0949	0.0879	-0.1428	0.1455	0.3265
Detroit vs other registries	0.7955	0.0758	<.0001	0.5247	0.1067	<.0001
Atlanta/Rural Georgia vs other registries	0.3155	0.093	0.0007	0.6255	0.1286	<.0001
Louisiana vs other registries	-0.0456	0.0759	0.5478	-0.1476	0.1131	0.1918
Males vs female	-0.2774	0.0497	<.0001	-0.4153	0.0719	<.0001
Never married vs married	-0.2249	0.0954	0.0184	-0.1877	0.1264	0.1376
Separated vs married	-0.0684	0.053	0.197	0.0362	0.0792	0.6478
Unknown marital status vs married	-0.1058	0.1901	0.5779	-0.0671	0.1839	0.715
Lung vs pancreatic cancer	-0.2271	0.0623	0.0003	-0.4156	0.0957	<.0001
Gastric vs pancreatic cancer	-0.2872	0.0997	0.004	-0.5138	0.1598	0.0013
Survival 0-1 month vs 12+ months	-1.1452	0.0745	<.0001	-0.6391	0.0949	<.0001
Survival 2-6 month vs 12+ months	-0.3405	0.0672	<.0001	-0.2753	0.0895	0.0021
Survival 6-12 month vs 12+ months	-0.1192	0.0779	0.1259	-0.0512	0.1118	0.6471
Regional vs localized disease	-0.3123	0.0564	<.0001	-0.374	0.0806	<.0001
Unknown vs localized disease	-0.0841	0.0715	0.2391	-0.1025	0.1397	0.4632
Age 70-74 vs 65-69	0.1199	0.064	0.0613	0.2507	0.108	0.0202
Age 75-79 vs 65-69	0.2031	0.0674	0.0026	0.3182	0.1069	0.0029
Age 80-84 vs 65-69	0.39	0.0759	<.0001	0.4691	0.1136	<.0001
Age 85+ vs 65-69	0.2891	0.0893	0.0012	0.6064	0.1255	<.0001
Rural vs non-rural	-0.2379	0.8862	0.7883	-1.0282	0.9329	0.2704
HMO vs FFS	1.1357	0.0712	<.0001	0.5862	0.0878	<.0001

Sensitivity Analyses

In addition to the results presented in the text, we performed several sensitivity analyses to assess the robustness of our results. We performed additional analyses to ensure that our conclusions were not sensitive to the choice of years or the exclusion of registries without adequate representation of all groups of interest. Results are presented below.

Table A2. Peters Belson estimates of the disparity in hospice use between black and non-Hispanic white pancreatic, lung and gastric cancer decedents (limted to registries where blacks comprise at least 5% of cancer patients—San Francisco, Detroit, Atlanta, Rural Georgia, Los Angeles (Atlanta and rural Geogria were grouped in the model because of small numbers from the Rural Georgia registry)

	1992-1995	1996-1999	2000-2003	2004-2008
Hospice Use				
Whites	40.5%	52.0%	60.6%	67.0%
Blacks unadjusted	31.3%	42.7%	51.3%	57.8%
Blacks predicted	35.3%	45.3%	55.7%	60.8%
Unadjusted disparity	9.2%	9.3%	9.3%	9.2%
Percent of disparity explained (se)	43.31% (0.93)	27.55% (0.98)	47.39% (0.99)	33.00% (1.0)
Quality Hospice Use				
Whites	26.5%	32.9%	36.3%	37.8%
Blacks unadjusted	20.9%	28.2%	31.7%	35.4%
Blacks predicted	23.6%	30.4%	34.4%	36.5%
Unadjusted disparity	5.6%	4.6%	4.5%	2.4%
Percent of disparity explained (se)	47.28% (0.83)	47.50% (0.89)	58.29% (0.95)	46.43% (1.0)

Table A3. Peters Belson estimates of the disparity in hospice use between black and non-Hispanic white pancreatic, lung and gastric cancer decedents (three year groupings)

	1993-1995	1996-1998	1999-2001	2002-2004	2005-2008
Hospice Use					
Whites	38.2%	48.4%	55.9%	60.7%	66.3%
Blacks unadjusted	32.8%	41.3%	48.5%	53.3%	57.4%
Blacks predicted	32.2%	41.5%	49.9%	54.9%	61.7%
Unadjusted disparity	5.3%	7.1%	7.4%	7.4%	8.8%
Percent of disparity explained (se)	-11.97% (1.04)	3.53% (0.70)	19.35% (0.69)	21.78% (0.76)	47.71% (0.97)
Quality Hospice Use					
Whites	26.3%	32.5%	36.4%	38.1%	40.5%
Blacks unadjusted	21.4%	27.8%	31.5%	32.2%	36.1%
Blacks predicted	25.1%	30.1%	35.1%	35.4%	41.8%
Unadjusted disparity	4.9%	4.8%	4.9%	5.9%	4.4%
Percent of disparity explained (se)	74.27% (1.76)	48.30% (0.66)	73.96% (0.75)	54.35% (0.78)	130.53% (1.2)

Table A3. Multiple logistic regression estimates predicting hospice use, by time period

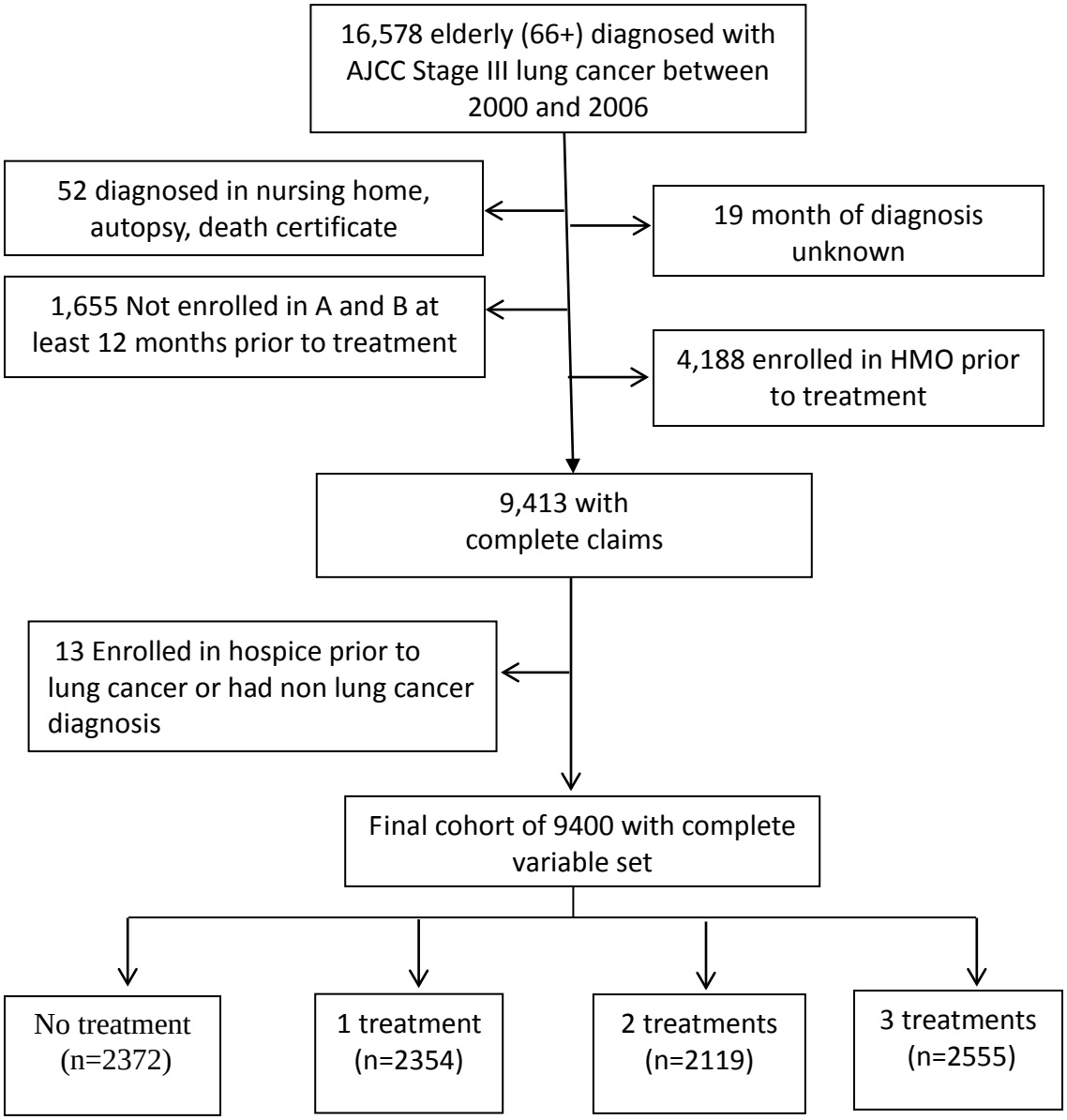
	1992-1995		1996-1999		2000-2003		2004-2008	
	OR	**p-value**	**OR**	**p-value**	**OR**	**p-value**	**OR**	**p-value**
Race								
NH-White	1.0	0.0014	1.0	0.0194	1.0	0.0605	1.0	0.1941
Black	0.808		0.876		0.905		0.936	
Median Income								
Q1	1.0	0.0202	1.0	0.0366	1.0	0.0018	1.0	0.151
Q2	1.062		1.083		1.023		1.007	
Q3	1.015		1.133		1.149		1.034	
Q4	1.184		1.163		1.177		1.109	
Education								
Q1	1.0	0.4171	1.0	0.9133	1.0	0.427	1.0	0.478
Q2	0.977		1.02		0.95		1.043	
Q3	1.026		1.031		0.969		1.07	
Q4	1.077		1.036		0.925		1.039	
Age at death								
65-69	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001
70-74	1.133		1.109		1.198		1.178	
75-79	1.13		1.134		1.33		1.342	
80-84	1.338		1.214		1.557		1.546	
85+	1.114		1.276		1.659		1.711	
Registry								
San		<0.0001		<0.0001		<0.0001		
Francisco	1.0		1.0		1.0		1.0	<0.0001
Atlanta	1.18		1.181		1.26		1.171	
Connecticut	0.858		0.726		0.785		0.726	
Detroit	1.556		1.191		1.156		0.866	
Atlanta	0.864		1.237		1.663		1.234	
Hawaii	0.656		0.98		0.986		0.818	
Iowa	1.401		1.554		1.656		1.584	
Los Angeles	0.849		0.754		0.88		0.737	
New Mexico	1.29		1.376		1.503		1.339	
San Jose	1.043		0.996		0.994		0.892	
Seattle	1.136		1.103		1.143		0.988	
Utah	0.482		1.146		1.683		1.449	
Sex								
Female	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001
Male	0.81		0.806		0.743		0.754	

Table A3 (continued). Multiple logistic regression estimates predicting hospice use, by time period

	1992-1995		1996-1999		2000-2003		2004-2008	
	OR	**p-value**	**OR**	**p-value**	**OR**	**p-value**	**OR**	
Marital Status								
Never Married	1.0	0.0438	1.0	0.0375	1.0	0.0166	1.0	0.0615
Married Previously Married	1.207		1.02		1.17		1.11	
Unknown	1.148		1.109		1.182		1.149	
	1.023		0.955		1.038		1.205	
Payment								
FFS	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001
HMO	2.199		1.622		1.454		1.401	
Stage								
Regional	1.0	0.0016	1.0	<0.0001	1.0	0.0002	1.0	<0.0001
Distant	1.162		1.17		1.135		1.157	
Unknown	1.12		1.218		1.162		1.269	
Survival								
0-1 month	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001
2-6 months	0.282		0.3		0.345		0.363	
7-12 months	0.907		1.018		1.112		1.164	
12+ months	0.897		0.973		1.068		1.027	
Cancer Type								
Lung	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001	1.0	<0.0001
Gastric	1.084		1.234		1.129		1.17	
Pancreatic	1.345		1.345		1.467		1.468	

Appendix B: Additional data and analyses for Paper 2

Figure B1. Cohort Ascertainment



Sensitivity analyses

The patient's date of death in Medicare does not always match the final discharge date in hospice for a few reasons: the patient may be discharged from hospice alive, the date of death recorded by Medicare may be incorrect (in some cases, it is recorded simply as the final day of the month of death),[1] or the date of discharge recorded by the hospice may be inaccurate. For 297 hospice users, the date of death did not match the discharge date from hospice. For 129 patients (46.9%), the date of death was within one week. For an additional 95 (34.5%) patients, the date of death was between 8 and 30 days different. Our analysis reports hospice length of stay, so inaccuracies may change our results. To assess this possibility, the analysis was run again excluding patients for whom the dates did not match.

The results that follow report our findings with these patients excluded.

Table B1. Codes used to identify treatments

Treatment	HCPCS	ICD-9	Revenue Center
Resection	32440, 32442, 32445, 32480, 32482, 32484, 32486, 32488, 32500, 32503, 32520, 32522, 32525, 32657, 32663	32.3, 32.4, 34.4, 32.5, 32.9	
Chemotherapy	96400-96459, Q0083, Q0084, Q0085, 90000-99999, 85000-89999, G0355-G0362, C9017, 50178, S9329, S9331		0331, 0332, 0335
Radiation	77750-77799, 0182T, 77418, 0073T, G0174, 77421, 77402-77416, 77520-77525, G0173, G0242, G0243, G0251, G0338, G0339, G0340, 0082T, 0083T		

[1] http://www.resdac.org/resconnect/articles/117

Table B2. Unadjusted frequency of hospice use by number of treatments

	Treatments				p-value
	0	1	2	3	
Total	2279	2282	2072	2492	
% who died before 2008	81.8%	77.7%	75.8%	67.0%	
Hospice use among those who died	54.7%	56.0%	52.7%	56.2%	0.1677

Table B3. Logistic regression model predicting hospice use*

		Odds Ratio	95% Confidence Interval		p-value
Treatments	0	0.883	0.766	1.018	0.1434
	1	0.918	0.796	1.06	
	2	0.846	0.734	0.976	
	3	1.0 (ref)			

*Covariates included in the model were: age, sex, race, registry, marital status, zip code income and education, stage(IIIa vs. IIIb), Charlson comorbidity score.

Table B4. Cox proportional hazards model predicting cancer specific mortality and time to hospice entry

		Cancer specific mortality				*Time to hospice*			
		Hazard Ratio	95% Confidence Interval		p-value	Hazard Ratio	95% Confidence Interval		p-value
Treatments	0	3.78	3.452	4.14	<.0001	3.359	3.131	3.603	<.0001
	1	1.853	1.692	2.029	<.0001	1.917	1.787	2.057	<.0001
	2	1.473	1.345	1.613	<.0001	1.541	1.437	1.652	<.0001
	3	1.0 (ref)				1.0 (ref)			

Table B5. Cox proportional hazards model predicting survival after hospice entry

		Cancer specific mortality			
		Hazard Ratio	95% Confidence Interval		p-value
Treatments	0	0.779	0.709	0.857	<.0001
	1	0.879	0.801	0.966	0.0072
	2	0.894	0.812	0.984	0.0215
	3	1.0 (ref)			

Table B6. Multivariate model of time to hospice, with death as a competing risk event

		Hazard Ratio	95% Confidence Interval	p value
Treatments	0	3.807	(3.485,4.159)	<.0001
	1	1.862	(1.704,2.034)	<.0001
	2	1.451	(1.327,1.586)	<.0001
	3	1 (ref)		

The high mortality rate in our cohort creates the possibility of bias in our Kaplan Meier estimates. We conducted a competing risks analysis, with death included as a competing event, to assess the sensitivity of our results to this method.

Figure B2. Competing risks analysis: unadjusted cumulative incidence of hospice use with death as a competing risk and censored at the end of the observation period.

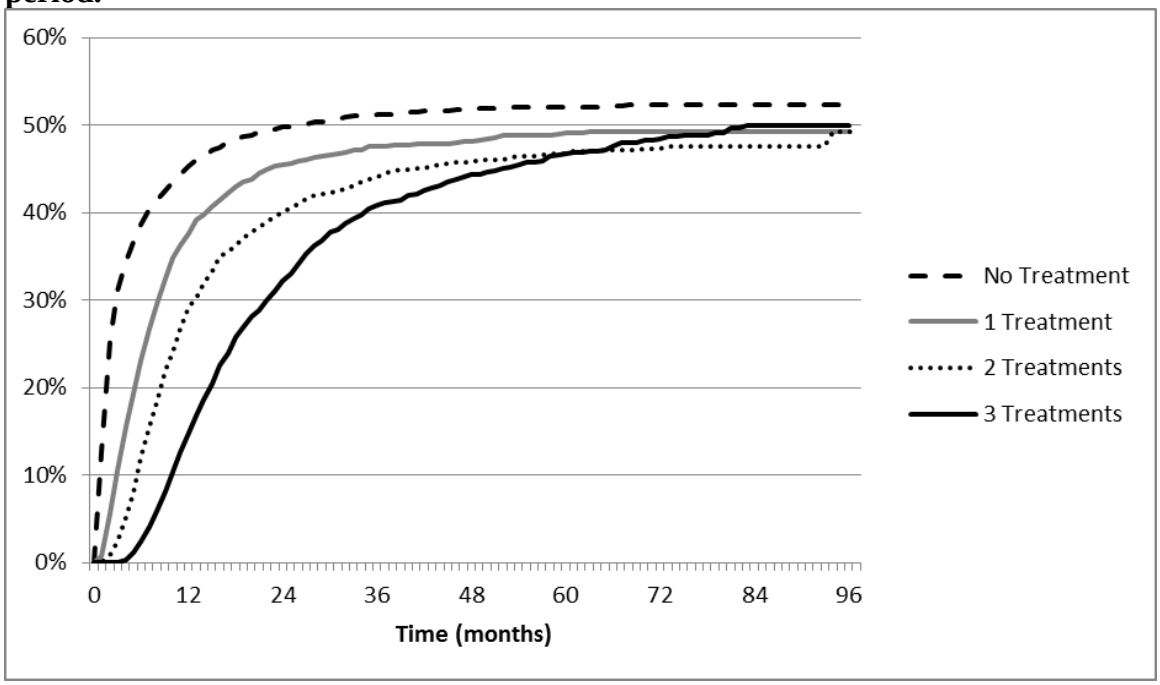


Table B7. Multivariate* Cox Proportional Hazards model predicting time to hospice with death as a competing risk event

		Cancer specific mortality			
		Hazard Ratio	95% Confidence Interval		p-value
Treatments	0	3.904	3.551	4.292	<.0001
	1	2.143	1.95	2.355	<.0001
	2	1.656	1.507	1.819	<.0001
	3	1.0 (ref)			

*Covariates included in the model were: age, sex, race, registry, marital status, zip code income and education, stage(IIIa vs. IIIb), Charlson comorbidity score.

Appendix C: Additional data and analyses for Paper 3

Figure C1. Cohort Ascertainment

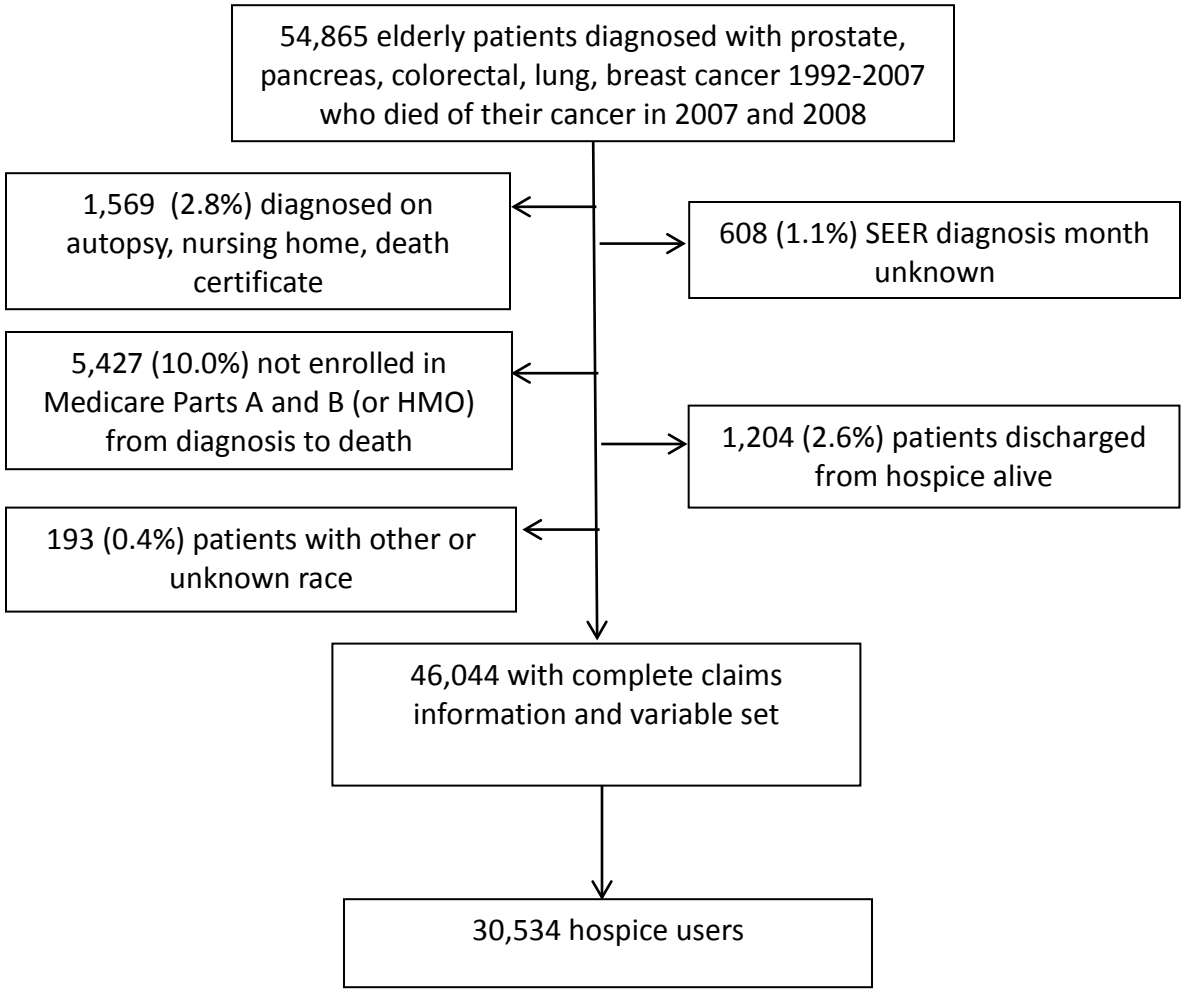


Table C1. Grouping of codes to make place of death variable.

CPT codes (HCPCS)	Location	N	Category	N
Q5001	Home	20,594	Home	21,412
Q5002	Assisted Living Facility	818		
Q5003	Non-skilled Nursing Home	1,738	Nursing Home	4,049
Q5004	Skilled Nursing Facility	2,311		
Q5005	Inpatient Hospital	1,960	Inpatient Hospital	1,960
Q5006	Inpatient Hospice facility	2,830	Inpatient Hospice	2,830
Q5007	Long Term Care Hospital	22	Other	283
Q5008	Inpatient Psychiatric Facility	0		
Q5009	Not Otherwise Specified	261		
Q5010	Hospice Facility*	n/a		n/a
	Total	30,534		30,534

*Code introduced in 2010 (after our period of study) to denote patients receiving care in a hospice residential facility (e.g., receiving routine home care while residing in a hospice facility).

n/a--not applicable